CONCEPTIONS OF "SUCCESS":

THE ETHICS AND RHETORIC OF HAND TRANSPLANTATION

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Twenty years since the first modern attempts at human hand transplantation (HTX) in 1998 and 1999, these operations are a fringe hybrid of the clinical specialties of reconstructive microsurgery and transplant immunology, offered only under experimental protocols in most cases. Despite having paved the way for face transplants, womb transplants, and penis transplants, fewer than 100 hand transplants have been performed so far, complicating clinical research efforts to parse results "objectively." Through ethnographic oral history fieldwork and close rhetorical analysis of the medical literature on hand transplantation, my dissertation argues that despite its ubiquity across hand transplant rhetorics, "success" is a misnomer and a distracting frame for discussions of effectiveness in the science and ethics of this field since the reality of lived experience for patients involves lifelong unfolding tradeoffs of medications management, care activities, surveillance, managed complications, and relational upkeep which are never fully resolved.

By placing the question of "success" in the frame of HTX patients' self-reported experiences of dis/ability and the ongoing construction of their identity—rather than in medicalized notions of function or ability and progress-oriented histories of transplant science internationally—I show that parsing cause and effect in a many-faceted procedure like hand transplantation is a nuanced task that betrays the inherent subjectivity of data interpretation in medical science. Following in the stream of discourse on narrative medicine, person-centered

healthcare, and the social construction of disability, my dissertation challenges norms for doctors representing vulnerable others to their colleagues and the public. Along with empirical insights from the oral histories, my analysis of hand transplant literature contributes to knowledge in disability studies, rhetoric of science, feminist bioethics, and science and technology studies (STS) bringing novel substance to 21st century debates about the options that should or should not be made available to those navigating the personal and putative binaries of ability/disability, beauty/deformity, and health/illness.

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1.0 INTRODUCTION

"Don't turn a scientific problem into a common love story."

~ Andrei Tarkovsky, *Solaris*

One night in February 2006, a chiropractor from Oklahoma was driving to a hunting trip with friends when his Suburban got trapped in a brush fire and its electrical systems failed, temporarily locking him inside the truck. Rich Edwards's hands were severely burned in the fire, remaining gnarled and nonfunctional even after several reconstructive surgery attempts. Deeply depressed, and desperate to recapture some aspect of his former lifestyle and vocation, Rich and his wife, Cindy, agreed to participate in an experimental double hand transplant in Louisville, Kentucky. Rich's singular desire was to go back to work as a chiropractor, stating in a post-transplant interview that, "If I can just get 50% feeling back, I think I can go in there and develop [my professional skills again]" (Ruppel, 2011).

Despite a surge of hope in the waiting period and a plethora of discreet functional gains per the hand grafts, Rich's depression gradually returned as he and Cindy realized how inadequate the transplant hands would be in terms of affording the redevelopment of chiropractic technique. While some gains in independence, social acceptance, and physical sensation was deeply meaningful to Rich and Cindy (being able to hold hands together and to pray, more bathroom autonomy, among other affordances), Rich's spirits again sunk to suicidal levels when he could

not return to work. At the end of summer 2015, Rich visited a gun range near his home and killed himself. Before his body was buried, Rich's hand grafts were surgically removed by two of the doctors who had originally performed his transplant (they traveled from Pennsylvania and Texas, respectively, to retrieve the hands). The hands were then transported to Pittsburgh, to be studied by transplant biologists at the University of Pittsburgh Medical Center (UPMC).

None of the speakers presented a robust picture of Rich and Cindy's experiences at the 2017 biannual congress of the International Society of Vascularized Composite Allotransplantation (ISVCA) in Salzburg, Austria—where almost every clinical thought leader researching hand transplantation was gathered, and at which I presented a poster on my oral history research with hand transplant patients and their caregivers. As a master's student in bioethics concurrent with my doctoral research, I found lack of discussion of the negative sequelae of Rich and Cindy's hand transplant questionable given the 2017 conference theme: "Defining Success."

My dissertation argues that the underappreciated and often, uncirculated narratives of hand transplantation (HTX) offer poignant complications to the media hype that tends to accompany any report of a hand transplant surgery. They also complement the abstract representation of experimental results as reported in academic case studies and review articles, where adverse consequences for patients can be obscured by the scientific tradition of discussing "objective" discreet and continuous variables like duration of transplant, grip function, and tissue health rather than holistically answering questions like: *Did this operation confer satisfaction? Did it facilitate life?* Because hand transplant surgeries are rare—highly active centers may average only one hand transplant every two years—practitioners trying to objectively compare methods and results find it difficult to generate statistically significant insights from published data. Disparate methodological approaches from center to center and high sociocultural variability among patients

internationally make the problem of evidence-based evaluation even more pronounced (Caplan et al, 2018). Nevertheless, a consistent refrain among hand transplant providers at conferences and in review articles is the "progress" of the HTX field and its evolution to other indications since the first modern cases in 1998 and 1999. Claims to successful hand transplantation in the academic literature are cited uncritically in sweeping retrospectives (Lanzetta et al, 2005; Gander et al, 2006; Elliott, Tintle, and Levin, 2014; Alolabi, Augustine, and Thoma, 2017; Cendales, 2017) and calls to further innovate (Baylis, 2004; Chambers, 2004; Brandacher, Lee, and Schneeberger, 2012; Ren and Laugel, 2013; Barker, Furr, Barrett, and Hardy, 2018).

In my dissertation I argue that despite its ubiquity across hand transplant rhetorics, "success" is a misnomer and a distracting frame for discussions of effectiveness in the science and ethics of this field since the reality of lived experience for patients involves lifelong unfolding tradeoffs of medications management, care activities, surveillance, managed complications, and relational upkeep which are never fully resolved. Through ethnographic oral history fieldwork and close rhetorical analysis of the medical literature on hand transplantation, my dissertation helps to address questions left open in case reports and reviews on these operations, such as: "What happened?" and, "What was it like?" for participants seeking to regain a particular quality of life through hand transplantation. By placing the question of "success" in the frame of HTX patients' self-reported experiences of dis/ability and the ongoing construction of their identity, I show through my research that parsing cause and effect in a many-faceted procedure like hand transplantation is a nuanced task that betrays the inherent subjectivity of data interpretation in medical science. Following in the stream of discourse on narrative medicine, person-centered healthcare, and disability studies—thinking especially through the concepts of

"biomedicalization" and the social model of disability—my dissertation challenges norms for doctors representing vulnerable others to their colleagues and the public.

Background

Since ancient times, physicians have attempted to repair dismembering injuries and illnesses in their patients using prosthetic substitutes and creative plastic surgery techniques. However, early surgeons were also aware that tissue from a stranger would "die" on the body of the recipient, a phenomenon they believed to be caused by the death of the donor's soul (Hamilton, 2012). Today, transplant immunology is a sophisticated field of research yielding drugs that suppress a transplant patient's natural immune responses in order to facilitate acceptance of organ(s) from another person. Unfortunately, transplant drugs are toxic and many transplant patients die or get seriously ill every year not from organ failure but from opportunistic infections that would not likely have been health threats had they not been taking immunosuppressants (Hatrick and Tonkin, 2001; Chelmonksi, Jablecki, and Szajerska, 2011; Hamilton, 2012). Immunosuppressants also bring heightened risk of diabetes and some cancers and are usually paired in hand transplant patients with steroidal treatments that bring a slew of unwanted side effects (Baumeister et al, 2004; Boratynska et al, 2014).

When I began working on this project in fall 2010, I spent time learning about the science of hand transplantation and familiarized myself with the history of these surgeries, which necessitated reading about the long period of public and professional debate on their ethical justification. While conducting research for my master's thesis, I interviewed several doctors and patients about their goals and experiences, discovering that in each individual case of hand transplantation, the ethics are complicated, because all organ transplants are life-altering surgeries that carry serious health risks. Far more than even novel forms of brain-controlled prosthetics, a

hand transplant is a daring attempt to "replace like with like," a phrase HTX doctors often quote, considered by many to be a basic principle of plastic surgery.

Modern hand transplantation was pioneered in Louisville, Kentucky, my hometown. These operations and their medical progeny (face transplants, penis transplants, abdominal transplants, and womb transplants), have inspired countless national and international media stories—including several on the prospect of a total head-body transplant, which is being envisioned by its proponents as a reasonable extension of the reconstructive transplant or "vascularized composite allotransplantation" (VCA) field (Ren and Laugel, 2012). The rapid evolution of VCA has occurred despite low numbers of patients internationally (N = <250) since 1998 and ongoing debate about the meaning of success for different VCA types including hand transplants. My dissertation will speak to and about these developments through my own observations and the words of experimental participants, making visible and accessible the human story of hand transplantation which is often elided in formal reports and histories.

Influences and significance

The problem of reduction in modern (western) medicine has received much attention from medical humanities, STS, and bioethics scholars in recent years. Stefen Timmermans and Marc Berg write, noting the increasing prevalence of "objective" measurements of effectiveness in the medical professions and the preference among clinicians for certain kinds of disembodied truth claims:

> According to the ideals of evidence-based medicine, clinical practice guidelines should be based on scientific evidence—preferably a meta-analysis of randomized clinical trials offering probability estimates of each outcome. Proponents of evidence-based medicine are wary of reasoning from basic principles or

> experience; they distrust claims based on expertise or pathophysiological models. They prefer to remain agnostic as to the reason why something should or should not work—rather, they objectively measure whether or not it works in real-life settings. Yet such evidence is only rarely available to cover all the decision moments of a guideline (2010, p. 3).

As Timmermans and Berg note, an attitude of resistance to non-quantifiable data has become deeply ingrained in the thought processes and protocols of western medical practice, yet high standards for what data "count" means some categories of knowledge of operations and outcomes may simply go unreported (for instance, the commonsense observations of patients or clinical staff members, as I argue in this dissertation).

My dissertation will extend discussion of unnecessary/unproductive reductionism in medical science by showing why grounded, "subjective," embodied data—which are discounted in strenuously quantitative clinical outcomes measurements—are crucial to the development of a more complete and accurate knowledge of relevant phenomena and events in the field of human hand transplantation. Without first-person representations of outcomes to balance biomedical accounts, I argue, the "mind's eye" of readers of hand transplant case studies may unintentionally assume a "clinical gaze" that is more focused on dependent variables than on human recovery from traumatic events. The progression of chapters in my dissertation—from the historical framing of ethical questions and quandaries in chapter 1 through the richly descriptive oral history accounts in chapter 2 (affording knowledge of the unending/unfolding challenges of HTX from patient families' perspective) to my final analysis of HTX "success" rhetorics in chapter 3—serves a performative function of "pulling back the curtain" on *what it means* for some aspects of hand transplantation to be emphasized over others in medical representations of success and failure.

Several scholars have recently investigated the media relationships and semiotic tools through which HTX and/or VCA doctors have represented themselves and their patients to the media (such as Fiona Kumari Campbell's comprehensive 2004 media diagnostic, "The case of Clint Hallam's wayward hand: Print media representations of the 'uncooperative' disabled patient", Haavi Morreim's 2004 article, "About Face: Downplaying the Role of the Press in Facial Transplantation Research" and Marjorie Kruvand's 2010 collaborative piece, "Face to face: How the Cleveland Clinic managed media relations for the first U.S. face transplant"). Other essays by medical humanities scholars and bioethicists have critically probed topics of meaning-making and value creation in VCA (such as Carson Strong's 2004 paper, "Should we be putting a good face on facial transplantation?" and Samuel Taylor-Alexander's 2013 article, "On face transplantation: Ethical slippage and quiet death in experimental biomedicine"). However, no books or papers on hand transplantation or VCA so far describe or theorize how "success" as a concept operates in the HTX literature, including what success is "doing" to afford or occasion certain ways of envisioning the goals and outcomes of hand transplantation as both the original VCA and as an emerging "standard of care" for upper extremity amputees (Breidenbach et al, 2015).

Historical researcher Mary Jo Festle has attended to the ambiguities of defining "success" in transplant science in her 2012 oral history of lung transplantation, *Second Wind*. The problem of uncertainty in these procedures—and the difficulty of straightforward outcomes evaluation—is carefully highlighted. Festle writes, "How should we decide whether a medical procedure is worthwhile? If patients gain an additional year of life, does that constitute 'success' or should we expect longer? Should we also consider the *quality* of that added time?" (p. 4). Festle's book outlines several issues impinging on success in lung transplantation, many of which are relevant to themes I explore in my dissertation. Where the value of Festle's book lies in its exhaustive

encyclopedic documentation of firsthand patient experiences, more so than critique, my treatment will move chapter by chapter toward developing a theory of how "success" operates rhetorically in the literature on human hand transplantation and why "success" is a distracting and destructive term of value in the parlance of HTX professionals.

As the first full length book project to focus on the rhetorical operations of success in hand transplantation/VCA, and to offer a view of these procedures from the "bottom up" utilizing data collected from patients' own accounts, my dissertation challenges the status quo for representation of experimental outcomes by clinical researchers (especially those working with vulnerable populations). My dissertation will contribute to disability studies, medical humanities, communication, STS, bioethics, and rhetoric both a new empirical study of high-visibility developments in recent medical history and several concepts with which to parse related stories. Along with empirical insights from oral history interviews with hand graft recipients and their caregivers in chapter 2, my analysis of hand transplant ethics and rhetoric in chapter 3 will bring novel substance to debates about autonomy and paternalism in the medical care of vulnerable populations and the options that should or should not be made available to those navigating the personal and putative binaries of ability/disability, beauty/deformity, and health/illness in the 21st century.

As disability scholar and literary theorist Rosemarie Garland-Thomson has written, in addition to directly manipulating our environment,

> Hands appear to help us conceptualize our world. Available items are on hand, handy, or in hand. Remarks can be made offhand. Disordered things are out of hand. Powerful people have the upper hand. … Human labor itself is signified by the hand. Workers are "hands." Fate is "the hand of God." The universe is "God's

> handiwork." Hands do the work of humanity, but they also serve us as visual emblems" (2009, p. 120).

The often breathtaking, sometimes brutally revealing words of scholars like Rosemarie Garland-Thomson and others in the growing field of disability studies (notably Fiona Kumari Campbell) have been my constant companions in undertaking this project. In addition to their important work critiquing medicalized responses to physical and cognitive forms of difference, disability scholars have exemplified why there can be, "Nothing about us without us!" in authentic representations of dis/abled lives—no matter who is speaking or from what position of expertise.

Oral historians, whom I consult for methodological tools for collecting and analyzing life stories (see chapter 2)—are similarly positioned towards esteeming the perspectives of people with firsthand experiences of an illness event or condition (rather than relying on top-down recitations of relevant factors). To develop my discussion of narrative forms and their value to ethical diagnosis, decision-making, and evaluation in hand transplantation I turn to feminist bioethicists such as Jackie Leach Scully and Margaret Shildrick, and scholars of narrative medicine and narrative ethics such as Rita Charon and Arthur Frank.

Normative bioethics and descriptive qualitative methods like oral history offer very different tools for parsing perennial problems in healthcare and for understanding what gives rise to medical disagreements and disparities. In my home field of communication and rhetoric of science, scholars deploy a capacious portfolio of resources toward disentangling the motives behind or interests served by explicit statements of surgeons and scientists. Together these tools and approaches are well suited to my analysis of HTX success claims in chapters 1 and 3, in which I re-present statements and publications of hand transplant professionals in light of what patients, themselves, have said is most important.

Other questions raised in my dissertation include: What are the challenges and opportunities of identity formation and preservation in the transition from "healthy" amputee to lifelong transplant "patient"? What is the intended or actual effect of the term "non-compliant" in medical parlance (especially in experimental settings)? What role do partners and caregivers play in the preparation and decision-making process for participation in hand transplantation (perhaps shedding light on the impact of critical support networks in procedures that are similarly high-risk/intensity)? How does the perceived need to be both "normal" and an "individual" in western society contribute to justifications for the biomedical restoration, transformation, or enhancement of bodies that have been amputated or physically disfigured?

Structure of the dissertation

Chapter 1 of my dissertation traces the discursive developments leading to the modern era of hand transplantation/VCA, introducing the problem of "success" and its characterization in the field since the late 1990s. The greatest academic innovation in the development of human hand transplantation, I argue, was the knowledge created through unprecedented collaboration of experts in transplant immunology/psychology and reconstructive plastic surgery in terms of sharing information relevant to the already-existing technical feasibility of performing a human hand graft. This is significant because the experimental permissibility of performing a "successful" hand transplant had to be *constructed rhetorically* by early HTX advocates, rather than emerging from a material kairotic moment afforded via discovery of a new drug or surgical strategy. The world's first modern hand transplants were thus produced through dialogical work in which appeals to beneficence and "quality of life" of disadvantaged patients played a crucial role. The last half of chapter 1 relates key events and academic representations of the first modern attempts

at hand transplantation and explores how these early cases figured in the establishment of hand transplantation as a field.

Chapter 2 complicates the picture drawn by hand transplant clinicians through eight oral history narratives, together offering an intimate portrait of life before and after hand transplantation. Part 1 of chapter 2 gives an introduction to my methodology, situating narrative oral history methods and grounded analysis of interview content within the context of qualitative research in medicine and medical humanities more broadly. Part 2 of chapter 2 is my empirical contribution to the literature on outcomes in hand transplantation in the form of eight narratives of hand transplantation based on my interpretation of oral history interviews, illuminated with quotes from narrators. Part 3 of chapter 2 gives a brief thematic extension to the oral histories by relating several noteworthy themes and concepts that arose through grounded analysis of collected data, most importantly the idea that "success" in hand transplantation begins with an accurate concept of the—in some ways, more limited—futures that are possible with and through hand transplantation.

Chapter 3 offers my view of the "rhetoric of success" in the medical literature on hand transplantation, arguing that success claims in this field are a distraction from the more pressing question of the specific tradeoffs experienced by patients and the effects of hand transplantation on their health and quality of life (QoL). In chapter 3, I bring together voices from disability studies and STS to support my final arguments on *why* patients' experiences are represented some ways and not others and why, in medical interventions where enhancing "quality of life" is the healers' sole commitment, "success" is a meaningless if not destructive term unless accessed within the framework of patients' own values and their conceptions of what it is or means. The grounded, infrastructurally-oriented critiques of STS scholars on major developments in medical science are

enlightening in terms of what values and material developments have facilitated different empirical commitments by clinicians and researchers. I argue in my treatment that critical understanding of the "rhetoric of success" in hand transplantation is aided by viewing hand transplantation as the biomedicalization of upper extremity disability where persons invest in a multi-level/multivalent process of self-transformation and I turn to disability scholars to unpack what this means for people who have lost a hand or both hands. Historically, chapter 3 picks up where chapter 1 leaves off, tracing recent movements in hand transplant ethics via close analysis of published editorials, case studies, and review articles, as well as talks by field leaders braced against my own observations.

I conclude the argument of my dissertation by calling for strategies to increase transparency among competitive research programs in the hand transplant field, and for the establishment of a formal patient advocacy and support network for HTX/VCA recipients and prospective candidates. As I argue in chapter 1, hand transplants were the original VCA promising life-altering "quality of life" improvements for patients despite immunosuppression—yet the nature of QoL effects in the lives of patient families are far more challenging, person-specific, complicated, and drawn-out than medical case studies and reviews represent (as I demonstrate in chapter 2 through my interpretation of patient narratives). The effect of these gaps in knowledge and even conflicting views on the range of outcomes for HTX has been almost nonexistent in terms of slowing professional enthusiasm for performing hand transplants and declaring their contributions to medical "progress" (chapter 3). It is therefore imperative that bioethicists, medical humanities scholars, and thought leaders in hand transplantation/VCA institute a new rhetorical standard for the representation of patients in their field; these efforts would in my opinion begin with the establishment of a patient advocacy and support group as well as field-wide agreements on strategies to improve data sharing and transparency.

2.0 A BRIEF AND DISQUIETING HISTORY OF HUMAN HAND TRANSPLANTATION

"Our patients aren't going to be concert pianists, you know."

~ Repeated saying among hand transplant researchers in Louisville KY, 2010-2011

In July 2016, two news articles about hand transplantation were published in international media outlets in England and the U.S. The first was from the BBC, "Double hand transplant: UK's first operation a 'tremendous' success," the second from *TIME* magazine, "*I can do absolutely nothing*: The first American with a double hand transplant wants them removed." The publication of these (albeit indirectly) contrasting headlines within days of each other suggests hand transplant outcomes or the claims connected with these surgeries may be highly variable case by case.

September 2018 marked 20 years since the first modern attempt at human hand transplantation. When I first began reading about these rare and complicated surgeries, I was a college student studying English and writing in Louisville, Kentucky. Hand transplants were a recurring topic in Louisville's *Courier-Journal* newspaper at the time, since several of the first modern attempts at hand transplantation were performed in Louisville in the late 90's and early 00's, and because Louisville doctor-researchers were pivotal to the establishment of the field. As a new orientation for organ transplantation presenting unique but risky rehabilitative opportunities for amputees, the possibility of carrying out life-changing reconstructive allografts brought novel ethical quandaries for transplant scientists and surgeons.

In this chapter of my dissertation I argue that, unlike the introduction of lifesaving solid organ transplants, it was primarily *rhetorical*, not scientific, invention which gave birth to the field of hand transplantation (HTX). In the first half of this chapter I trace transformations in the possibility and permissibility of hand transplantation as constructed by field "pioneers," noting key moments in the discourse on HTX where dialogue and textual intervention occasioned new ways of imagining medical responses to hand loss. First, I attend to the unprecedented interdisciplinary cooperation which illuminated previously cloistered knowledges of transplantologists and hand surgeons, and how as a unified group these hand transplant hopefuls performed the rhetorical and ekphrastic work of visualizing HTX operations as dramatic improvements to future recipients' quality of life (QoL) where monumental gains to QoL could be conceived as outweighing the drawbacks of immunosuppression. The second half of the chapter covers the establishment of hand transplantation as a field of medical research, including discussion on the mixed outcomes of early experimental HTX cases and the way these were interpreted as evidence that hand transplants can be successful. The very notion that "quality of life" could be a site of intervention for organ transplantation has been called "a quiet revolution in organ transplant ethics" by prominent bioethics scholars. Because almost all of the rhetorical heavy lifting giving rise to and sustaining the field of hand transplantation relies on the promise of "beneficence," or the idea that HTX present an opportunity to improve the QoL of a vulnerable population of care seekers despite the known burdens of immunosuppression and steroids, I argue in the conclusion of this chapter that in-depth first-person, qualitative research is needed to illuminate tradeoffs for patients.

2.1 TRANSPLANTING HUMAN HANDS: PRECLINICAL OBSTACLES AND OPPORTUNITIES

Organ transplantation has for many years been the standard of care for life-threatening conditions such as heart, liver, and kidney failure, because statistically significant longitudinal studies of tens of thousands of organ transplants since the late-1900's have depicted organ recipients living longer lives with fewer health complications than those with the same underlying condition who did not get a transplant (Hamilton, 2012). However, it was not clear to researchers in the preclinical years of hand transplantation that the benefits of graft hands would outweigh their financial, physical, and possibly psychological, costs (Lee and Mathes, 1999; Foucher, 1999; Jones, 2002). While toxic drugs that impair immune activity may be a reasonable burden for people suffering organ failure who would likely die without a transplant, people living without hands might not want to risk iatrogenic complications and possibly death for quality-of-life gains in functionality and aesthetics.

When considering these risks, advocates of hand transplantation had to navigate the reality that in addition to being risky and possibly life-shortening, people living without a hand or both hands have access to aesthetic and bionic prosthetics (although many users abandon these devices as not especially helpful or practical in their daily lives) (Kay and Wilks, 2013). Some bioethicists voiced further concerns that hand grafts could damage the public image of transplant medicine if they ended badly for patients. "The risk associated with extending transplantation to organs that are not directly lifesaving," writes Cleveland Clinic ethicist George Agich, "is that such extension might compromise the ethical legitimacy of the entire transplantation enterprise and could ultimately adversely affect organ donation" (2003, p. 142).

Early hopes for hand transplantation were greatly burdened by memories of a failed hand transplant in Ecuador in 1964, in which the patient's immune system quickly attacked and destroyed the transplanted tissue. Advocates of hand transplantation have cited primitive immunosuppressants as the reason for the failure of this first recorded attempt: "Despite the use of systemic steroids and azathioprine [in 1964 in Ecuador], severe rejection developed 2 weeks after the operation and amputation was performed. The development of more efficacious and mechanistically driven immunotherapy in the 1980s moved the possibility of successful [hand transplantation] closer to reality" (Ravindra, McKinney, Xu, and Ildstad, 2009, p. 3519-3520). Although steady advances in immunosuppressant medications were made throughout the 70's, 80's and early 90's, largely cynical attitudes on the potential for hand transplants persisted as animal model experiments did not appear to show promise for human application (Jones, Breidenbach, Barker, and Gruber, 1999; Ruppel, 2011).

By the time hand transplants were again being seriously considered for trials in a human patient, life-extending solid organ transplantation and reconstructive microsurgery were both well-developed fields of clinical care and scientific research, making hand transplantation a project that depended not on the development of new tools but on demonstrating the maturity and efficacy of existing ones (Barker and Markmann, 2003). HTX researchers in the late 90s began to argue that for the right patient, successful hand transplantation was basically a matter of balancing quality of life gains in function with the drawbacks of immunosuppression. "Hand transplantation may be a landmark for society, but it is not a major surgical or immunological advance," write plastic surgeons and limb transplant researchers Shehan Hettiaratchy, Peter Butler, and W. P. Andrew Lee in 2001. "Surgeons have had the technical ability to reattach amputated parts of the upper limb for over 30 years. … Similarly, hand transplants do not herald a breakthrough in transplant

immunology. [Modern] immunosuppressant drugs mean that rejection can be prevented of even very antigenic tissues" (2001, p. 494; see also Kann and Hewitt, 2001). Rather than waiting for a major advance in immunomodulatory technology to attempt a human hand transplant, the field of modern hand transplantation began when researchers realized that, "[t]he crux of the matter is how much immunosuppression can be justified for a non-life-saving-procedure?" (ibid.), which effectively reshaped the scientific barrier into a rhetorical one.

Scientific challenges: Building "proof of concept" for HTX with existing tools

The first serious public and academic debates on hand transplantation as a clinical possibility were initiated by a group of hand surgeons and transplant doctors at Jewish Hospital in Louisville, Kentucky, in the late 1990's. The group, led by surgeons in the celebrated Kleinert Kutz Hand Center, were funded by a grant from Jewish Hospital to pursue the next groundbreaking innovation in hand surgery and the group chose hand transplantation as their target of exploration. In a retrospective chapter for a clinical textbook on hand transplantation, members of the Louisville team describe the world's first successful hand transplant as a goal towards which they began to strive inviting the participation of international colleagues and peer communities:

> In June 1996, we organized a team of surgeons comprising hand, plastic, and transplant specialties along with members representing transplant psychiatry, pathology, tissue typing, hand therapy, and organ procurement. This constituted the Louisville Hand Transplant team. In November 1997, the First International Symposium on Composite Tissue Allotransplantation was convened in Louisville, Kentucky. The goal of this meeting was to discuss the scientific, clinical and ethical barriers standing in the way of performing the first human hand transplant (2008, p. 215).

A dominating anxiety among the Louisville hand transplant team, and other limb transplant researchers at the time, concerned the biological complexity of the human hand—not its psychosocial intricacies or the challenges of sourcing an "external" (visible and social) organ graft. Composed of muscle, bone, nerve, blood, and skin, hands as "composite tissues" were thought to require higher levels of immunosuppression than internal organs of comparatively more homogenous tissue type. Gordon Tobin, a biomedical scientist who worked with the Louisville team, retrospectively describes the state of knowledge at that time, "Virtually all investigators believed that epithelium [skin] had such great antigenicity that it was insurmountable by immunosuppressive drugs" (Tobin et al, 2009, p. 467). Tobin has also said that, "Most of us [on the Louisville Hand Transplant Team] were skeptical that [our project] would come to anything in the near future. From the 60's through the 90's, it was universally believed that skin was too antigenic to transplant. The literature was very discouraging. There had been some success with mice, but their immune system is so different from ours that no one would take those results and think they would be transferrable in humans" (interview with Tobin, 2010).

The Louisville group perceived that unless they could achieve graft longevity with regular amounts of immunosuppression (for instance, the same quantities used in kidney transplants), hand transplantation would never be seen as ethically allowable due to the serious side effects of transplant medications. Even at therapeutic levels, immunosuppressant drugs can cause nephrotoxicity (kidney damage), diabetes, weight gain, are linked to higher rates of some cancers, and make transplant patients more susceptible to opportunistic infections and disease (Brenner et al, 2002). The effects of a more-aggressive-than-average immunosuppressive regimen on an otherwise healthy body were seen as too detrimental to justify a non-life-saving transplant (Tobin et al, 2005). Other issues that remained to be considered included the fact that a transplant hand,

unlike a heart or kidney, would not be immediately functional, yet would be visible all the time (Klapheke, Marcell, Taliaferro, and Creamer, 2000). Years of work-intensive physical therapy (four to six hours a day for up to two years) would be required to keep the muscles on a graft hand from atrophying in the healing process, and to stimulate communication between the donor hand and the recipient's brain (Bueno et al, 2014; Hartzell et al, 2011). The burden of adaptation and compliance would be shared by the patient *and* their family members, which was difficult to envision (interview with Martin Klapheke, 2010). For all of these reasons, the potential benefits of a biological reconstructive option such as a transplant hand had to be explicitly articulated and compared to existing alternatives.

In order to demonstrate scientific proof of concept, the Jewish Hospital doctors partnered with researchers at the University of Louisville to conduct large-animal limb graft experiments in which they deployed standard immunosuppressive protocols to determine the tissue- and life-preserving efficacy of contemporary transplant drugs for use in complex "organs" like hands (Jones, Breidenbach, Barker, and Gruber, 1999). They also performed an extensive literature review. The lead surgeon on the Louisville team, Warren Breidenbach III, worked with colleagues in transplant medicine to conduct the review. He has described this process as challenging due to the disparity of approaches used by scientists at the time. Breidenbach says, "I couldn't make any sense of [these papers]. Someone would do an experiment with drug A and B, someone else B and C… The first person might do it for 60 days and stop, the next maybe 30 days. It was hard to synthesize a consistent theme." However, he says, "[Ultimately] it was shocking—by time we finished literature review, it was completely clear that every tissue in the human hand had already been successfully transplanted with normal doses of immunosuppression. Many of the articles had flown below the radar even though they shouldn't have" (interview with Breidenbach, 2010).

Ethical challenges: Balancing risks and benefits in terms of "quality of life"

The scientific challenges of hand transplantation were closely tied to the ethics of immunosuppression in an otherwise healthy patient. Bioethicists working with the Louisville group and attending their conferences grappled with the question of whether it would be morally permissible to subject willing candidates to lifelong dependence on toxic pharmaceuticals simply to correct an unwanted condition of physical difference (Siegler, 1998; Dickenson and Hakim, 1999; Simmons, 2000). Concurrent with the literature review and large animal trials, the Louisville group hired transplant ethicist Mark Siegler to serve as an outside-observer at several of their meetings and to help them identify philosophical and social implications. With Siegler's counsel, the Louisville group developed a strategy for proceeding that included public and professional debate as well as rigorous patient selection and preparation protocols (Cooney et al, 2018; Tobin et al, 2009). As Tobin has said, "In innovative medicine, being demonstrative and clear allows the public and other professionals to weigh in with their critiques and suggestions long before you put a patient on the table. It also protects investigators from doing something for their own glory rather than for the good of the patient" (interview with Tobin, 2010). Siegler guided the team in their efforts to remain transparent and establish the best possible environment for success. Siegler writes that in his own estimation, he weighed the question of risk in hand transplantation with the principles of beneficence and autonomy: "is improving the patient's quality of life (as determined by the patient) sufficient grounds to allow patients to risk morbidity and mortality? The answer is clearly 'yes' because such trade-offs are inevitable and are not unique to hand transplantation. In fact, people make trade-offs in their everyday life between quality of life (in their terms) and risk" (Siegler, 1998, p. 2781).

After the Louisville Hand Transplant team established scientific viability and worked through the ethical issues with international experts at conferences and in the literature, they began looking for a suitable patient candidate. Hundreds of people with upper limb amputations applied for the role. The team eventually chose Matt Scott, a New Jersey unilateral amputee and paramedic who expressed strong disaffiliation with his brain-controlled prosthesis as too heavy, too cumbersome, and not "human" enough—despite his ability to successfully use it. Empirical tests of Scott's candidacy included numerous physicals and extensive bloodwork. The team contacted Scott's insurance company to ensure all of his post-transplant drugs and therapy would be covered for as long as the graft survived. Scott was informed repeatedly that the operation had every chance of failing, and to mitigate any irrational hopes that might undermine his understanding of those odds, Scott was required to appoint a "patient advocate," defined by the Louisville group as a college-educated person with a trusting relationship with the prospective patient who genuinely cares for them and who would be willing to scrutinize all aspects of the process including the institutional preparedness for a surgery of this kind. Finally, the candidate's psychosocial health was evaluated by a specialist in transplant psychology, Martin Klapheke (Ruppel, 2011; Tobin et al, 2009).

Tobin explains the hand transplant team's extreme scrutiny of their patient as necessary for novel medical interventions that are also dangerous: "These days [identifying the risks and benefits of hand transplantation] is easier because we have a good measure of success, but when we were first working on this, there was none of that. To Dr. Breidenbach's credit, he was very, very honest with the candidates. He said, 'I give it about a fifty-fifty chance of [turning black and] 'falling off' within a year, and you might not have any function at all, and you could *die*.' I thought that was very straightforward of him not to over-represent the results" (interview with Tobin, 2010). Paul

Simmons, an ethicist who worked with the Louisville group, recalls of this process that they placed, "a high priority on professional and public discussions" which included symposia in Louisville, Vancouver, and Chicago between 1997 and 1999, at which internationally recognized experts in hand surgery, transplantation, immunology, and bioethics debated "every aspect of the procedure, even before a protocol was submitted to the IRB" (2000, p. 462).

The predicament of the first hand transplant candidates may have been dire if the treatment failed, but it was not likely to have been as severe as the situation faced by the first heart, kidney, and liver recipients, due to the non-lethal nature of limb loss as a medical condition. Indeed, "In hand transplantation, immunosuppression can be abruptly terminated when a life-threatening complication arises, and the hand can be amputated if necessary" (Baumeister et al 2004, p. 102). In the case of the world's first modern attempt at hand transplantation, this was the tragic—albeit not fatal—result.

The first modern hand transplants: Rival efforts in Louisville and Lyon

The Louisville hand transplant team learned late that they had been in competition to perform the world's first successful hand transplant. In September 1998, an international team of surgeons in Lyon, France, carried out the operation on their patient, a businessman from New Zealand named Clint Hallam. "As it turned out, the effort for 'public display' had the effect of notifying the world of the intention to be first with the procedure and thus encouraging others to beat them to the draw," writes Simmons, "Thus, the first hand transplant took place not in Louisville, but Lyons, France" (2000, p. 462).

Nadey Hakim, a member of the Lyon team, writes that his colleagues had been contemplating a hand transplant long before the Louisville Hand Transplant team converged on the idea:

> Earl Owen, world-renowned pioneer of microsurgery and a good friend of mine, first voiced the idea of a hand transplant more than 30 years ago at a speech at Edinburgh University, but it was not until the mid-1990s that he decided it was both technically and immunologically possible … Earl was keen to form a team of experts in preparation for the procedure, so I suggested we contact Jean Michel-Dubernard in Lyon, Head of Transplantation and urology at the city's Edouard Herriot Hospital, where Earl had been a visiting professor for 20 years … [Dubernard] was excited by Earl's suggestion and agreed that the proposed forearm transplant could go ahead in his department in Lyons. Earl quietly began assembling a skilled international team comprised of transplant, orthopaedic and hand microsurgeons, anaesthetists, a psychiatrist and a psychologist specialising in body image disturbances (Hakim, 2006, p. 1-2 in Hakim, Owen, and Dubernard, 2006).

Several members of Lyon group had participated in conferences or followed the proceedings published by the Louisville team. Jean-Michel Dubernard agreed with Earl Owen that the scientific and ethical justifications offered by the Louisville group and others were sufficient to justify an experiment in humans. Together they presented this argument to the Ethics Committee of Lyon University and to the Edouard Herriott Hospital's patient protection board. Both committees approved the procedure; Owen and Dubernard finished assembling their team, and chose a patient as well as a time to convene for the operation. In a chapter for a book on transplant history published in Greek and English, Dubernard reflects on various developments leading to the first modern attempt at hand transplantation, "In April 1998, the final decision to go ahead was taken. … Earl and I chose September as a suitable month for the operation. Ironically, at a meeting

on composite tissue allografts held in Louisville in 1997, John Barker said during his concluding remarks that the time had come to 'just do it.' The account of this meeting was published in *Transplantation Proceedings*. We received the issue in Lyon in September 1998! Indeed the time had really come to just do it" (2011, p. 36).

However, some aspects of the Lyon group's inaugural attempt at hand transplantation are curiously out of sync with the apparent scrupulousness of the Louisville group in terms of selecting and preparing their patient for a deeply invasive and highly visible experimental procedure:

> Earl [Owen] and Clint [Hallam] arrived in Lyon in early September. They stayed at the Reine Astrid Hotel where [our team's psychiatrist] Gabriel Burloux joined us and immediately disappeared into Clint's room. Earl and I waited patiently in the lobby but with growing anxiety as nearly two hours passed. When Gabriel finally emerged, he gave us the green light. He agreed to take charge of Clint and come whenever it was necessary during the pre-and postoperative period. We needed a donor as soon as possible, but our procurement area was restricted by Didier Houssin to the Rhöne-Alpes region around Lyon (6.5 million inhabitants). The regional ABM team was highly motivated, yet I badgered its doctors and nurses day in, day out. My routine everyday activities kept me busy but Earl was going round in circles. We rehearsed all the steps of the operative procedure on cadavers until we knew them inside out. Anxiety was rising. Finally, we decided that if no donor came up by the end of September, we would cancel the attempt. … Money was a problem. Clint was supposed to arrive with enough money to cover hospital costs. He said that he had put it in his suitcase, but the suitcase which was in the hold of the British Airways aircraft during the flight from Sydney to London had

> been lost. I called British Airways several times but was told that no suitcase had been registered on his departure from Sydney. Clint admitted that he could not muster the necessary funds. He was virtually penniless. We forgave him for lying on the grounds that he was so determined to have the transplant, but doubts about his behavior nevertheless persisted (2011, p. 36).

Dubernard was able to secure enough funds to perform the operation by going to a personal friend and research sponsor, Charles Merrieux, for help. Almost immediately after Merrieux agreed, a suitable donor hand was found, and the international team of surgeons Dubernard had assembled for the operation—an all-star cast from France, England, Italy, and Australia—were called to come in for the procedure (Hakim, Owen, and Dubernard, 2006; Ruppel, 2011).

Unfortunately, Clint Hallam expressed displeasure with the outcome of the hand transplant and requested removal two years later. At first none of his doctors would agree to perform the amputation. Hallam allegedly toured various institutions in the U.S. seeking removal of the graft, but finally Nadey Hakim agreed to perform the amputation in London in February, 2001 (Ruppel 2011). In a quote from a *New York Times* article called "A Short, Speckled History of a Transplanted Hand," published February 27, 2001, physician and writer Lawrence K. Altman editorializes that, "From beginning to end, Clint Hallam's landmark hand transplant embarrassed nearly everyone involved. The story began in September 1998 when Mr. Hallam, then 48, flew halfway around the world from his home in Perth, Australia, for the operation in Lyon, France. … The story ended on Feb. 2 in London. In 90 minutes, Dr. Nadey Hakim amputated the very hand that he had helped attach and that Mr. Hallam had sought so desperately but did not do enough to keep." Among the acknowledgements granted Clint Hallam following his tenure as a groundbreaking experimental hand transplant patient, he is the first man in history to lose his right

hand three times (first in a buzz saw accident, next in a failed replant of his original hand, third after losing his transplanted hand)—as originally pointed out in a news article by the UK paper *The Observer*. This bit of trivia is compellingly bizarre and unexpected, but more importantly for the argument of my dissertation, it suggests a great deal of suffering on the part of the patient.

In a personal reflection on his role in various transplant firsts, Jean-Michel Dubernard describes his frustration with the behavior of his patient, makes a bizarre conjecture as to the reason for Hallam's eventual disaffection with the hand transplant process, and reflects in a markedly wistful tenor that, had Hallam been a better patient, the graft tissue might have survived longer:

> Clint was most cooperative and amiable during the first three months after surgery. His wife and children came to visit him at Christmas and returned to Perth in early January. Clint was supposed to meet up with them and Earl three days later. Then he disappeared. We knew that he was in the United States as he was regularly appearing on TV and in the newspapers … Clint had always shown streaks of brilliance but his behavior was difficult to understand. When he discovered that Denis C., the bilateral hand transplant, [sic] had had an audience with Pope John-Paul II, he also went to Rome but he failed to meet the pope. He was very disappointed. Was this why he discontinued treatment in September 2000? Palmira Petruzzo, an Italian vascular surgeon and member of our team, took great pains to persuade him to resume the drugs but to no avail. One month after discontinuation [of his transplant drugs], the signs of rejection were still only moderate. They disappeared rapidly on treatment but so did the patient. In the end, the hand was amputated by Nadey Hakim in London in February 2001. According to Jean

> Kanitakis, our pathologist who examined the graft, rejection could still have been reversible (2001, p. 37).

In his own accounting of the Lyon team's experiences, Nadey Hakim provides a more strenuously passive, yet similarly success-oriented interpretation of the events leading up to and following Clint Hallam's hand transplant (and misses not a beat before claiming that the logical next step for their research team would be to attempt an even more challenging and hazardous bilateral hand transplant):

> The surgery was successful, and so was the adherence to the immunosuppressive regime which has started preoperatively with intravenous anti-lymphocyte serum and first doses of the immunosuppressive cocktail of drugs. "My hand's back," said Hallam on emerging from the anaesthetic. "It's almost like I lost an old friend years ago, and suddenly it's back." Congratulations arrived from Jaques Chiraq, the French President. Dan Rather, CBS News presenter, stated, "It's the kind of quantum leap in modern medicine that, when it happens, is stunning" … Clint Hallam left the hospital on January 1, 1999, assuring us that he would be continuing the very satisfactory progress of his transplant and was expected to return to Australia for continuation of the protocol. It was now the team's task to perform the first successful double arm transplant—another world's first!" (Hakim, 2006, p. 5 in Hakim, Owen, and Dubernard, 2006).

In the above accounts and in nearly all other early reporting of the Lyon team's first attempt at hand transplant, Clint Hallam's pain and hardships take a back seat to his criminal identity and lack of compliance with his clinicians' (by definition, ad hoc) hand transplant protocol. While it is true that at the time of his hand transplant surgery in Lyon, Hallam was wanted in several countries

for fraud, denouncement of Hallam's character by his clinicians (taken up by commenters in the media) make the whole scenario appear to be Hallam's fault, rather than his doctors' fault based on rushed preparation, lack of transparency, and inadequate exit strategy (Campbell, 2004; Ruppel, 2011).

Disability studies scholar Fiona Kumari Campbell has written a capacious and profoundly critical account of the Lyon group's public representations of Clint Hallam's experiences in their first hand transplant experiment; Campbell's is the best synopsis I have found of the media reports coming out around this time:

> The Clint Hallam international surgical soap-opera which played out in the electronic and print media during 1998–2000 is an apt example of the ways in which contemporary technological practices interface with both popular and technical formations of what it means to be 'dis-abled' and 'nearly-abled'. … [In this case] the contentious nature of the surgical experiment is erased and evaporates in media reports to be replaced by the underlying theme of the marvels of medical discovery, 'gift-giving' (narratives of optimism), and Clint's ungrateful 'deviant' response… the experience and insights of Clint Hallam [are] not generally addressed and [are] consistently erased (Campbell 2004, p. 444).

As Campbell points out, it is striking how little energy is expended in the above accounts considering the motives, interests, suffering, and even firsthand experiences of the world's first modern hand transplant patient.

Transplanted six months later than Clint Hallam in January, 1999, the candidate in Louisville, Matt Scott, was by most accounts better selected and better prepared than the French patient. Scott now possesses the long-surviving hand allograft of over 20 years and frequently

appears at meetings to articulate his satisfaction with the outcome—this despite the fact that in the days after receiving the transplant hand, tabloid snooping revealed that the donated hand came from a man who had been convicted of manslaughter, and whose death occurred via suicide (Ruppel, 2011).

2.2 THE ESTABLISHMENT OF A MEDICAL FIELD: REPRESENTING EARLY EXPERIENCES IN HAND TRANSPLANTATION

Parsing cause and effect in many-faceted procedures like hand transplantation is a nuanced task that betrays the inherent subjectivity of data interpretation in medical science. In the rest of this chapter I will show how, when recounting the history of hand transplantation in editorials, review articles, and other publications, field leaders and observing peers have given fundamentally different interpretations of the first successful case of hand transplantation, and why this affects both scientific knowledge in the field today and public understanding of the value of hand transplantation and other types of VCA.

The world's first successful hand transplant

Today, Matt Scott is unanimously recognized as the worlds "most successful" hand transplant patient having enjoyed high satisfaction with his graft for over 20 years. A special event at the 2018 American Society of Reconstructive Transplantation (ASRT) publicly honored Matt for his efforts and progress and thanked him for ambassadorship in the field. Nevertheless, when speaking of the "world's first successful hand transplant" today, doctors and journalists must take pains to clarify whether they mean the Lyon or the Louisville attempt. Frustratingly, in very few

of the academic or public-facing texts recounting the history and ethics of hand transplants and VCA do authors give an account of how they reconstructed relevant events or awarded primacy to successful "firsts." See, for example, this quote in a paper by hand surgeons Mendenhall, Brown, Ben-Amotz, Neumeister, and Levin, which glosses the history of HTX/VCA giving primacy to the Lyon group's 1998 hand transplant, without mentioning the hand transplants that were attempted in Ecuador and in Louisville: "Many advancements in VCA have taken place since *the first hand transplantation was performed in Lyon, France*, 2 decades ago" (2018, accessed online). A more recent paper acknowledges the Ecuador hand transplant and awards "success" to Matt Scott, but completely skips over the 1998 Lyon hand transplant on the way to Louisville in 1999: "*in 1964, a hand transplant was performed in Ecuador* on a sailor who had lost both arms in an explosion… However, the patient's graft *was rejected and was explanted* at week 3. The field was stagnant until the 1980s, when the discovery of calcineurin inhibitors improved immunotherapy and made limb transplantation viable. *In 1999, a hand was transplanted with longterm success in Louisville*, Kentucky, reawakening interest in CTA and reconstructive transplantation. By 2009, 53 successful hand transplants had been performed worldwide" (Reece and Ackah, 2019, p. 63). According to a recent review article by Canadian hand surgeons Noor Alolabi, Haley Augustine, and Achilles Thoma, which gives a history of the hand transplant field,

> The first *attempted* hand transplantation was performed in Ecuador in 1964. The transplant survived 2 weeks but *was lost to acute rejection* … In 1998, the second hand transplant was performed in Lyon, France. The *patient ultimately lost the transplant* after 2 years because of rejection secondary to medication noncompliance. Following this, the *first successful hand transplant* with long-term

survivability was performed in Louisville, Kentucky, in 1999 (2017, p. 23; italics added).

Of note in the above passage by Alolabi, Augustine, and Thoma, the authors give credit to the Louisville group's work by writing that the "first successful hand transplant" occurred in Louisville in 1999—whereas the Lyon transplant is *not* described as having ever been successful. How the authors structure the source of adverse outcomes is also interesting: in their description of the historical attempt in 1964, that hand graft "was lost" (passive voice) to "acute rejection"—clearly a medical cause for failure as immunosuppressants were underdeveloped at the time. The Lyon failure, however, is narrated in active voice: "The *patient ultimately lost* the transplant" and there can be no question regarding why: "secondary to medication noncompliance." (See UPMC/Johns Hopkins researchers Jaime Shores, Gerald Brandacher and Andrew Lee 2015 for a similar synopsis.)

Researchers in the Louisville group have published their own versions of the early world experience in hand transplantation. In the following quote from a 2009 paper, Tobin and colleagues skip mentioning the hand transplant attempt in Ecuador in 1964, award their patient robust accolades for his superior results in the 2000s, and account for Clint Hallam's graft loss as having resulted from poor clinical preparation rather than his own "noncompliance":

> The first 2 hand CTAs provided paradigms defining subsequent world experience. The Louisville patient was carefully selected with thorough psychological screening, preparation, and family involvement. He was disciplined in rehabilitation, in taking medication, and in ongoing monitoring … The single exception to the Western experience was the first recipient of the team in Lyon. … The procedure went well, but *the recipient prematurely left the care of his*

> *physicians against advice* … Two years after transplantation, he requested amputation from members of the original team. … Thus, all hand allograft losses to date have come from either *poor psychological screening* or *loss of access* to immunosuppression, and success correlates with thorough psychosocial screening, preoperative education, intense rehabilitation therapy, assurance of ongoing medications, and close follow-up" (p. 468, italics added).

In another paper, the Louisville group offers a more succinct verdict on the matter of Clint Hallam and the world's first successful hand transplant: "It is the Louisville team's view that *failure could have been prevented* by careful screening and a thorough psychosocial and psychiatric evaluation of this candidate" (Brown et al, 2007, p. 359). Notable in the above accounts is how authors characterize responsibility for unsuccessful hand transplants. Whereas Alolabi, Augustine, and Thoma continue a tradition of blaming the patient, the Louisville group places responsibility in the hands of doctor-researchers (failed preparation).

One of the most thorough and "objective" regularly published reports on the outcomes of hand transplants and other reconstructive transplants is a collaborative update called the "International Registry on Hand and Composite Tissue Transplantation" (IRHCTA). In an early publication of the Registry in 2006, authors write that, "Of the 23 hands transplanted, all were viable at 1 year after transplantation; then 8 graft failures occurred, *caused by rejection in a noncompliant patient* [Clint Hallam] and in the Chinese patients who did not take the immunosuppressive treatment" (Lanzetta et al, p. 481, italics added). Perhaps because the authors on this review include representatives from the Louisville and Lyon programs, as well as providers who started programs in China, Poland, Italy, and Austria, all 23 hand transplants performed up to that time are described as having been "viable" at 1 year following the procedure. Although authors

acknowledge and seemingly agree that, "8 graft failures occurred," the source of failure is located explicitly "in a noncompliant patient" or in patients' decisions not to follow medical protocols.

Interestingly, in our interview for the oral history project that informs my dissertation, Matt Scott described to me his ambivalent feelings about the superlative nature of his medical achievement and his conflict over the treatment of Clint Hallam by doctors and media representatives: "I just happened to be 'successful' because [my hand graft has] lasted the longest. Honestly, I think Clint, for all his troubles and all his tribulations that he had afterwards, I think that he was an incredibly brave soul, whatever his motivations were... I owe Clint a world of gratitude for being the first one to get out there and do it, to be the first one to be criticized as heavily as he was criticized" (oral history interview with Scott, 2015).

Establishing a medical field: The evolution of hand transplantation

In a 2001 paper for *The Lancet* titled, "Lessons from Hand Transplantations," several hand surgeons with early interest in hand transplantation describe the contentious climate on the topic of hand transplantation closely following the Lyon and Louisville cases: "In the aftermath of the failure of the first hand transplant, surgeons and patient have traded accusations. He did not comply with the therapy, allege the surgeons; my body has had enough, counters the patient. Essentially they are both illustrating the same point: immunosuppression for a non-vital, highly antigenic transplant is verging on the edge of what is acceptable" (Hettiaratchy, Butler, and Lee, p.495). Further complicating the picture of the early global experience in hand transplantation are the relatively underreported hand grafts performed in China closely following the Louisville and Lyon attempts, in which a change to the Chinese medical system apparently caused loss of access to immunosuppressant medications among all the patients; rejection followed inevitably (Tobin et al, 2009). These early losses, while acknowledged as failures by thought leaders in the field, have not

seemed to slow the growth of hand transplantation in terms of discouraging the establishment of HTX programs around the world.

Today over seventy hand transplant operations have been performed worldwide, and they have also led to transplants of the face, abdominal wall, penis, and womb (Kollar et al, 2018). Nevertheless, hand transplants are still innovative medicine, offered only under research protocols in many places, though recently some field leaders have argued HTX has a solid history of success to the point where it is no longer merely a "transitional" therapy (as argued by Chim et al, 2014), but "is moving from acceptance as an ethical surgical experiment to the standard of care." Contemporary hand transplants advocates write that, "[these surgeries] 'proved to be better than anticipated, now raising the issue of whether hand transplantation is the standard of care … [based on the fact that] … Complications were less than originally predicted, the hands obtained good function, and long-term allograft survival was demonstrated" (Breidenbach et al 2015, p. 367). Shores, Brandacher and Lee essentially agree, although they resist "standard of care" terminology: "Hand and upper extremity transplantation has demonstrated sufficient improvement in function and quality of life that it should no longer be considered purely 'experimental'" (2015, p. 357e).

Unfortunately, despite vaunting claims in the literature and optimistic rhetoric from field pioneers in retrospectives and reviews, the actual factors affecting or indicating success in a particular case of HTX remain unclear in these papers. After almost 20 years of case studies and clinical research, ascertaining the appropriate indications and methods for evaluation in hand transplantation are vexing tasks for practitioners; some authors have advocated taking excess caution in preparing hand transplant patients before surgery, and zealous care in providing them with follow-up for as long as they have their hand graft (Dumont, Sann, and Gazarian, 2017, p. 150). Many in the field still emphasize the importance of finding the "right" patients to ensure

success (which seems to conflict with the idea that hand transplantation could be a "standard of care" for any patient population). In a 2010 paper on implementation procedures for VCA in the U.S., Linda Cendales, also an early member of the Louisville program, and colleagues write that, "the importance of patient selection and a multidisciplinary evaluation process cannot be overemphasized" (Cendales, 2010, p. 14). Samuel Taylor-Alexander, a medical anthropologist who has written extensively on the policy developments allowing for the rapid expansion of hand transplantation to other indications, has critiqued the heavy stress placed on finding "ideal" patient candidates for these high-cost, high risk reconstructive interventions (Taylor-Alexander, 2014).

Oral histories of hand transplantation: The need for in-depth firsthand accounts

It is well understood and widely agreed in the literature on hand transplantation that the singular goal of a hand transplant is improving the life of a candidate-patient (Siegler, 1998; Simmons, 2000; Dickenson and Widdershoven, 2001; Hettiaratchy and Butler, 2001; Tobin et al, 2005; Baylis, 2004; Caplan and Purves, 2017). Because hand transplantation necessitates not only a serious surgical procedure but a grueling therapy schedule, an invasive pharmaceutical regimen, and lifelong commitment to caring for the graft, it would seem impossible to know whether, and if so, how, hand transplants enhance recipients' lives without in-depth firsthand accounts of that person's experiences before and after the intervention. The biologically and emotionally complex aspects of receiving and living with organs from another person—especially social organs like hands—calls for attention to the feelings of patients about their experiences, not just medical monitoring of their adherence to research protocols (Svenaeus, 2012; Neukom et al, 2012; Williams et al, 2016; Shildrick, Carnie, Wright et al, 2017).

In a recent review of VCA ethics, Caplan et al explain the importance of accurate, in-depth outcomes reporting to the development of clinically successful VCA programs:

> Maintaining comprehensive data in standardized, transparent formats will be key to long-term viability of the field. VCA has to date been characterized by competition among pioneering centers across the globe … This environment sometimes rewards self-promotion in data reporting. … While the field has made preliminary steps toward aggregating data, much work remains to ensure fairness by developing transparent eligibility criteria, uniform sharing of protocols and outcomes data, establishing patient centered advocacy programs, and updating current laws (2018, online first).

According to UK hand transplant surgeons Simon Kay and Daniel Wilks, efforts toward data collection and transparency of the kind recommended by Caplan and colleagues have not yet been robust in the HTX/VCA field: "Of the large number of [hand and face] transplants completed now, *outcome data of value is to be found in few*," (2013, p. 1457, italics added). Similar observations on a lack of helpful outcomes data in the behavioral health literature were published by HTX psychiatrists Martin Kumnig and colleagues in a 2012 review paper. Kumnig et al. write that, "Despite a thorough analysis of the literature, the lack of relevant published information in the psychosocial domain of transplanted patients is a significant limitation … The majority of articles do not address the psychosocial assessment in any greater than passing detail, so the conclusion that can be made from these highly descriptive, mostly empiric studies in the current literature is limited" (p. 425). More recently, the poor quality of outcomes reporting in the hand transplant field has been remarked on by HTX practitioners and healthcare policy and effectiveness researchers in Canada and North Carolina (Health Quality Ontario, 2016, p. 3; Hedges and Rosoff, 2018, p. 2).

While there have been some attempts to describe transformations in the health and quality of life of HTX patients using self-reported, survey-based methods or thematic analysis of

psychiatric semi-structured interviews (Bachmann, 2007; Jensen et al, 2012; Kumnig and Jowsey-Gregoire, 2016), these approaches do not necessarily perform the essential work of describing "what happened" and "what it was like" for recipients and their families before and after hand transplant surgery. In a 2012 review titled, "Quality of Life Considerations in Upper Limb Transplantation," psychologist and science studies Salley E. Jensen and colleagues consulted approximately 250 academic papers on hand transplantation to determine QoL effectiveness, of which 27 were included for analysis in their study having "quality of life" as the main topic. However, only 3 of these 27 papers included interviews with hand graft recipients as part of their methodology. None of the studies were conducted using open-ended questioning techniques by non-program-affiliated researchers, and none of them quoted patients directly regarding their experiences. In some cases, no attempt was made to approach experimental participants for their point of view even when the stated goals of the research were compatible with doing so. In one such study, Slatman and Widdershoven conduct what they call a "phenomenological narrative" analysis of the first two hand transplants in Europe. Because the authors, "were not in a position to collect information from face–to-face interviews," they conducted their analysis using data collected entirely from news media accounts. Slatman and Widdershoven acknowledge that in their phenomenology of hand transplantation, "empirical analysis of embodied self-experience is limited" (2010, p. 72).

Hand transplant textbooks seem to make more space than peer-reviewed journal articles for patient perspectives. In *The Science of Reconstructive Transplantation*, (ed Gerald Brandacher, 2015), an early chapter featuring exposition on, "The Daily Life of a Hand Transplant Recipient" (p. 45) offers an account of HTX challenges and opportunities as told by a patient recipient. The article is written in first person and details the process of evaluation and recovery, including day-

to-day challenges and opportunities and general reflections. It is an interesting and helpful account in many respects but limited in its empirical utility as textbook editors do not attempt to describe the process of inclusion and development of this narrative (i.e., editorial and authorial decisions about preparation and representation including why this narrative was chosen from among other HTX narratives).

In a chapter for the textbook, *Hand Transplantation*, (ed. Marco Lanzetta and Jean-Michel Dubernard), Daniele Bachmann writes on the topic of "Quality of Life in Hand Transplant Patients." Although Bachmann did conduct psychiatric interviews with hand transplant recipients, sufficient to yield insights on their motivations and experiences, Bachmann's chapter spans only three pages of the 400+ page textbook in which it is published and does not offer quotes from patients, nor long-term retrospective follow-up on how the side effects and complications from transplant drugs, and the recovery process, balance against gains of psychosocial considerations or manual functionality. Bachmann writes:

> [T]ransplantation of hands changes the patient's body in a radical way; he does not get his own hands back (we say "he" because all transplanted patients thus far have been men), nor does he return to a previous state. The recipient has to make the donor hands his own, and, even with the recovery of motor functions and sensitivity, these hands are forever present before the patient's eyes … The hands are also highly charged with meaning in the human being's imagination: …What, for example, did the donor's hands do before his death, during moments of intimacy? The patient's ability to integrate the transplants is also dependent on the reaction of the close family circle, which could display feelings of rejection, of

> disgust or worry, or, on the other hand, could be quite happy for the patient and give him vital support in accepting the transplant (2007, p. 365).

In this passage Bachmann alludes to several potential avenues of deep concern and interest regarding the post-transplant lives of people with hand grafts. Disappointingly, the chapter's conclusion follows soon after revelations that transplant hands change the recipient's own body in "a radical way"; that hand grafts are "highly charged with meaning"; and that the patient's pleasure in owning the hands depends heavily on the acceptance of others. Readers can only wonder at the sentiments Bachmann's patients may have expressed that would lead to such compelling statements because the interviews are not published alongside professional analysis.

Conclusion

Hand transplants were the ground-breaking surgeries in the field of vascularized composite allotransplantation (including transplants of the face, abdominal wall, penis, and uterus, all of which are now being performed internationally)—thus arguments promoting positive evaluation of early VCA operations can be considered, themselves, *successful* in eliciting support for what is now a well-evolved field of chronic care medicine. As I argue above, hand transplants received major coverage in news media even though they represented minimal achievement surgically and scientifically—the biggest advance in the field was interdisciplinary coordination and reconsideration of ethical norms and this work was accomplished *discursively*. Because distinguishing success from failure in life-enhancing procedures like hand transplantation is a complex process requiring several means of interpretation, yet few to no studies of hand transplantation have so far used a multi-dimensional, qualitative approach to analysis of HTX outcomes, my project could be helpful in recognizing hindrances to clarity and reliability across different rhetorical venues and audiences.

My oral history research, presented in the next chapter of this dissertation, offers a view of hand transplantation from the "bottom up" providing balance and richness to abstract medical characterizations of success and adding context to contradictory views among professionals. As ethicist Paul Simmons wrote in the early days of hand transplantation, "The benefits of [hand transplant operations] do not lend themselves to quantification… [Hand transplant patients] speak from experience and weighty matters of importance to them that relate to relations with loved ones, intensely personal losses and a sense of what is worth it when an opportunity for restoration presents itself" (2000, p. 459-460). The oral history summaries and analysis of interviews with hand transplant patients, which I present in chapter 2, help us to think through lingering questions of risk and benefit that were the focus of early ethical debates on hand transplantation, such as: Will a hand transplant be worth the effort and cost? Under what conditions and for what indications are hand transplants most likely to be successful? To whom should hand transplants be offered and through what tools should their effectiveness be measured?

3.0 AN ORAL HISTORY OF HAND TRANSPLANTATION: NARRATIVE REPRESENTATIONS OF EXPERIMENTAL OUTCOMES

"When we got a moment alone, in [the hospital room following double hand transplant surgery], we looked at each other and were like, 'Wow, these are—beautiful—like, they're so *hot*.' [Laughing]…is the only thing we could say because, we had like, mere seconds before somebody came in the room, to sort of to acknowledge to each other that, we *loved* the arms."

~ Angel Gonzales, partner/caregiver of a double hand transplant recipient

"I wondered how it would actually feel—how odd is that going to be—to have another man's hands touching me? I can tell you that is not a factor at all. From the moment they're on, they're his hands, moving those hands and using those hands with his own mind and his own heart. The hand is just the physical instrument. Him touching me and him holding me and all that, it's coming from Rich—his heart, his emotions. To me, from day one, they were his hands."

~ Cindy Edwards, widow of a double hand transplant patient

In recent decades, narrative methods for research and clinical assessment have gained consideration in a range of academic and health sciences disciplines. Investigators and specialists with vastly different skill sets, values, and approaches to generating meaning have argued for the inclusion of narrative inquiry as a viable means of knowledge generation in their work or research (Charon, 2001; Coulehan, 2003; Geisler, 2006; Webster and Mertova, 2008; Woods, 2011; Alnaes, 2012; Neukom et al, 2012; Brockman, 2013; Cudney, 2014; Peek, 2016; Constant and Roberts, 2017; Hurwitz and Bates, 2018). In primary and chronic care medicine, in particular, calls for attention to narratives and narrative processes have increased in frequency and prominence

(Editors, 2007; Sgro, 2016; Charon, 2016; Murphy and Franz, 2016; Shildrick et al, 2017). Physician and founder of the "narrative medicine" movement, Rita Charon, has argued that patient narratives are not merely ornament to the scientific medical record but an irreducible feature of medical diagnosis and decision-making, writing, "Clinicians have always at least implicitly understood that the most fertile and clinically salient information we derive about patients comes from listening to them talking about their illnesses" (2006, p. 192). Disability scholar and sociologist Arthur Frank has similarly stated the importance of evaluating ethical situations in healthcare through stories, explaining that, "When other people's values are stated abstractly, these values are compelling only to those who already agree with them. When these values are situated in stories, that may not lessen the inherent tragedy, but at least this tragedy can be recognized and shared" (2016, p. 21; see also Jonsen and Toulmin, 1988, "Prologue" to *The Abuse of Casuistry)*

In this chapter of my dissertation I show how narrative methods can be helpful for improving current understandings of the goals and limitations of hand transplantation (HTX) as a response to chronic disability of the upper extremity. After introducing several opportunities and limitations of narrative inquiry for understanding HTX, I present eight narratives of hand transplantation based on my oral history interviews with seventeen hand transplant recipients or their closest caregivers. The oral history project contains honest, profound, and deeply intimate portraits of the lives of hand transplant patients and their families, before and in some cases long after surgery. Their testimony describes a broad range of the functional, aesthetic, and emotional ramifications of receiving and caring for a single or double hand transplant; in many ways, these personal reflections from the patients' perspective provide a foil for the empirically oriented, progress-driven narratives of hand transplant and "vascularized composite allotransplantation" (VCA) articulated by field professionals writing in academic journals (see chapter 1). Far from the

currently accepted straightforward, "objective" accounting of outcomes comprising assessment practices in the majority of papers on HTX outcomes, where benefits to patients are related in detached technoscientific parlance, the multi-dimensional meaning of hand transplantation as a quality of life enhancing operation is here illuminated by the life stories of patients, where comprehensive notions of "normalcy," health, and happiness, rather than merely organ function and survival, constitute "success." In the third and final section of the chapter I discuss three themes that arose through iterative coding of narrative data, most importantly the idea that claims to "success" in hand transplantation should begin and end with patients' own understanding of what these operations afford and mean to them.

3.1 ORAL HISTORIES OF HEALTH AND MEDICINE: CULTIVATING AND SHARING PATIENT PERSPECTIVES

Long before the expression "narrative medicine" was appointed to describe a methodology and a movement in 21st century medicine, psychiatrist and anthropologist Arthur Kleinman was among those protesting reductive accounts of human illness and disease that characterized the "medical gaze" (Foucault and Sheridan, 1973) of the late 1900s. In *The Illness Narratives,* Kleinman censures strenuously scientific depictions of the physician's role in these conceptualizations as dehumanizing to those seeking care, writing, "The everyday priority structure of medical training and of healthcare delivery, with its radically materialist pursuit of the biological mechanism of disease … disables the healer and disempowers the chronically ill" (1988, p. 9). According to narrative medicine and narrative ethics practitioners, the advantages of patient storytelling and its counterpart, critical listening, are practical and immediate: the patient's

experience of illness/disorder becomes a valuable source of knowledge both framing and emerging within the clinical setting. Importantly, "narrative medicine" is *not* aimed at gathering patient stories with a view to entertaining and informing the public (especially as representation in this vein risks exploiting patients) (Campbell, 2004; Charon, 2006; Shakespeare, 1996; Wiltshire, 1999).

Despite apparent enthusiasm for narrative methods in many healthcare circles, the idea that patient narratives are more subjective or prone to bias than decontextualized biomedical accounts of events and procedures is still widespread among healthcare providers. Rita Charon reminds readers that, "'At the risk of sounding anecdotal' is the preface to much of the story-telling that goes on in medicine, and students or clinicians who take the time to hear patients out are thought of as either poorly trained or daft" (2006, p. 192). The extent to which narratives of illness can be considered empirical data informing clinical research depends on the goals of the discourse and the methods of narrative researchers. For instance, subjective firsthand impressions from patients would not be as effective as straightforward numerical measurements for tracking and describing certain aspects of postoperative management in hand transplantation, such as kidney function over time while on immunosuppressants. Additionally, a single narrative case study published in a medical journal or textbook which relates in emotional detail the experiences of a particular patient could be informative, but could also be a source of unbalanced representation, distracting from other types of stories and experiences. Thus the "situatedness" of narratives in the context of other informing data, which may include different historical accounts, academic or scientific studies, news articles, firsthand observations, etc., is important to take into consideration when working with narrative data. As bioethicist Christine Mitchell has written, "although stories convey ethical values and entail ethical responsibilities, they import ethical principles and norms that exist apart

from the stories themselves and warrant consideration beyond the tools of narrative analysis" (2014, p. s13). Narrative researchers must be clear to outline their approach to collection of data and give an account of how they have established internal or external validity in their representation of narrators and narrated events.

Whereas narrative medicine and narrative bioethics can be productive towards knowledge generation in the clinical setting without the cases under discussion being widely shared, the audiences for medical oral history research are typically external, as the creation of a historic document for edification of publics is the primary objective (Yow, 2015). The collection of oral history transcripts, and researcher interpretations or summaries, are tasks oriented toward publication of narratives or their integration into projects that can transport them beyond the academic research context. Many oral histories are archived so that the testimony of narrators can be studied in its original form, and some are protected and archived for sharing with a future audience (Yow, 2015). In the introduction to the edited volume, *Oral History, Health and Welfare*, Paul Thompson argues that using oral history techniques in any field can bring special advantages to researchers: "[Oral histories] allow us to explore those crucial areas of life which the written record scarcely touches: the private world of family relationships, for example, and all the influences from childhood onwards which go into the shaping of a professional life, and the often crucial support of partner and family through adulthood" (in Bornat 2000, p. 3). This more-intimate view of events or phenomena can be especially useful to medical humanities researchers. Thompson continues, "Oral history can delve into the hidden world of the institution, the clinic or the hospital, revealing the daily experience of routines and treatments as told by the subjects, clients or patients at the receiving end of services" (in Bornat 2000, p. 4).

The hand transplant narratives interpreted in this chapter demonstrate the relevance and usefulness of narrative accounts to the clinical process and to scientific knowledge. Despite the variation in the narratives below—indeed perhaps because of that variation—examination of the experience of living with transplanted hands can help inform scientific and social evaluations of the risks and benefits of these procedures. As medical humanities researchers Valerie Kalitzkus and Peter F. Matthiessen argue, "Because the language and lifeworld of patients and physicians can be so far apart, it might be helpful to have an intermediary… [or a] … facilitator between the physician's and the patient's world" (2009, 85). As an intermediary or interpreter of patient experiences in hand transplantation, oral history is an apt tool, especially given its framing of the object of concern within the life narrative of the recipient or caregiver (rather than occurring as part of a metanarrative of transplantation or medical science). To discover (for example) how power dynamics may have contributed to the deterioration of a clinically necessary relationship, or how disappointment after failure to regain a desired function could have weighed on a hand transplant patient as they struggled to maintain their responsibilities as part of research protocols, can give valuable context and empathic possibility to medical accounts of relevant sequelae.

As oral historian of lung transplantation Mary Jo Festle has written, oral history interviews are especially useful for parsing questions of "quality of life" in medicine and healthcare:

> Although quality of life is by definition a subjective phenomenon, thus far the fields of medicine, psychology, and social work have tended to rely upon quantitative survey-based data to evaluate it. These are useful and help the field to make generalizations about whether transplants are worthwhile, but they also have limitations … Oral history interviews nicely complement the quantitative data, while at the same time alleviating some of the problems with surveys. Since they

> are characterized by open-ended questions, oral history interviews allows people to provide fuller and more detailed description and to supply their own definitions of quality (2012, p. 10).

Indeed, writes Paul Thompson, "To include a user's perspective of health and welfare in today's practice of oral history is not simply a question of adding a complementary source to match documentary evidence." Rather, oral histories of health and medicine are, more likely to, "challenge and subvert understandings of care and control, the boundaries between health and welfare, the location of centres and margins and notions of status and eligibility in all sectors of society and conditions of life" (in Bornat, 2014, p. 8).

Although other qualitative methodologies such as cross-sectional survey research and open-ended interviews can elicit story-telling and descriptive statements from research participants, only narrative methods are explicitly aimed at understanding the complete picture of an event or topic from the "ground level" so to speak. And to understand how a speaker's life history shapes their experiences and their reflections on their experiences. Ideally for highly cooperative, dynamic interventions like hand transplantations, a more observationally rich, ethnographic methodology than oral history interviewing (incorporating direct observations on patient and family routines for care, etc.) might be most revealing in terms of illuminating the factors eliciting quality of life effects following transplant of a hand or both hands. However, scholars have noted the time-consuming nature of even the most basic narrative inquiry in medicine, thus more robustly experiential research may be difficult to support (Kalitzkus and Matthiessen, 2009, p. 86).

3.2 NARRATIVE REPRESENTATIONS OF HAND TRANSPLANTATION: EIGHT ORAL HISTORIES

The eight narratives of hand transplantation related below are summaries of first-person oral history interviews conducted with hand transplant patients and their closest caregivers, primarily during the summer of 2015. Participants in the oral history project include single and double hand transplant recipients at various temporal distances from their transplant (including an interview with Matt Scott, recipient of the longest-surviving hand graft at ~20 years). Oral history interviews were carried out using a script of open-ended questions beginning with inquiries about the narrators' early life, and carried out in one-on-one, extensive conversations ranging from 50-140 minutes per interview. Caregivers and family members were interviewed separately from direct recipients of hand grafts which provided additional context, richness, and complexity to the accounts. Approximately 10-30 minutes at the beginning of every interview were spent talking about the narrator's childhood and family or vocational background. Framing the topic of concern—in this case the outcomes of hand transplants—with discussion of the narrator's early life and interests is typical of the oral history approach and helps anchor recorded testimony more strongly in the narrator's own speech and values (Yow, 2015).

Data gathering for this project commenced in April 2015. I began grounded analysis of oral history interviews as they were recorded and transcribed, with early descriptive codes informing the development of different and more sophisticated research questions as the project progressed. By December 2015, all transcriptions were compiled into a master document (organized by order of completion of the interviews) so that as codes evolved and narrative summaries were written, relevant portions of narrators' testimony could be easily referenced and compared using the search

function in Word. As links between common ideas or story types began to emerge by comparing key points or linguistic structures, preliminary thematic observations could be made. For instance, early in the process of conducting interviews, I noticed that on the question of whether hand recipients and their families had difficulty accepting the donated "secondhand" nature of their own or their partner's hand graft, almost every narrator described feelings of identification and affiliation that were unexpectedly robust. This appeared to me significant because HTX patients' potential emotional disaffiliation from their graft hand(s) was a major concern of early hand transplant providers (see first epigraph) and because this phenomenological Q&A emerges uniquely within the field of hand transplantation/VCA, since life-extending solid organs work automatically without the need for patients' conscious participation. From the document containing compiled interviews and codes I created a codebook in Excel. Managing coded data in an Excel spreadsheet was efficient and allowed great flexibility in terms of sorting and visualizing codes and their references by topic or life phase. To do this I followed recommendations given in a Texas A&M tutorial on qualitative data management published on YouTube: (https://www.youtube.com/watch?v=1EzJj6efF_c).

Other activities informing my grounded theory of hand transplantation include close rhetorical reading in the literature on hand transplantation, attendance at two international and one national meeting on VCA science and ethics (in April 2015, October 2017, and November 2018) and through my ongoing collaborations with clinical providers of hand transplantation conferring broad practical knowledge of hand transplant protocols and health policy developments. Clinicians and scientists I have formally interviewed to increase my knowledge of hand transplant policies and procedures include: plastic surgeon and VCA biologist Mario Solari (UPMC, Pittsburgh); transplant psychiatrist Andrea DiMartini (UPMC, Pittsburgh); hand surgeon and VCA researcher

Warren Breidenbach III (San Antonio, formerly Jewish Hospital, Louisville); plastic surgeon and VCA researcher Curt Cetrulo (Massachusetts General Hospital, Boston); plastic surgeon and VCA researcher Scott Levin (University of Pennsylvania, Philadelphia); plastic surgeon and VCA researcher Vijay Gorantla (Wake Forest University, Winston-Salem, formerly Jewish Hospital, Louisville and UPMC, Pittsburgh); plastic surgeon and VCA biologist Jan Plock (University of Zurich, Switzerland); plastic surgeon and hand transplant researcher Daniel Wilks (Leeds Teaching Hospital, England); VCA biologist Gordon Tobin (University of Louisville, interviewed in 2010); plastic surgeon and VCA researcher Bohdan Pomahac (Brigham and Women's Hospital, Boston, interviewed in 2010); plastic surgeon and VCA researcher Simon Talbot (Brigham and Women's Hospital, Boston, interviewed in 2010); transplant surgeon and VCA researcher Jean-Michel Dubernard (Lyon University, France, interviewed in 2011); transplant psychologist and hand transplant psychiatrist Martin Klapheke (Jewish Hospital, Louisville, interviewed in 2010); hand transplant coordinator Brenda Blair (Jewish Hospital, Louisville, interviewed in 2010); and immunologist and hand transplant researcher Christina Kaufman (Jewish Hospital, Louisville, interviewed in 2010).

As Charlotte Linde writes in *Life Stories: The creation of coherence,* "Life stories express our sense of self: who we are and how we got that way. They are also one very important means by which we communicate this sense of self and negotiate it with others" (1993, p. 1). Nevertheless some people do not find it natural to imagine the episodes, events, and sensations of their life in a "neat" story-like fashion. Although medical humanities scholar Angela Woods has recently argued that, "[We should] not presuppose an orientation towards storytelling or narrative self-presentation" among subjects of qualitative research, (Woods, 2011, p. 76) my mostly chronological script of questions reflecting my needs as an oral history researcher did not leave

much room for creative or otherwise non-narrative self-representation by oral history narrators in this project. As much as possible, I tried to let narrators speak for themselves and associate events creatively in the latter questions of the interview which asked for more "gestalt" or comprehensive reflections. For efficiency and readability in the interpretations below, I aimed for a "middle" level of abstraction and have added light commentary where I felt some extension would be advantageous to parsing key aspects of a narrative.

Narrative 1: Matt Scott

Before becoming the world's first indisputably successful hand transplant patient, Matt Scott owned and used an Otto Bock myoelectric prosthetic hand, one of the best brain-controlled devices available for non-biological restoration of hand function. During a phone interview in October 2010, Scott told me,

> Having a prosthetic just wasn't the same. Don't get me wrong—the prosthetic served me well. It served me *very* well. I was able to become a top paramedic in my field, (with some adjustments), and I got married and fathered two kids. I was successful in the ways we define 'success.' But mine was a traumatic amputation, you know, and after thirteen years of having a prosthetic, I had grown so dissociated with it that I'd come to detest it."

Matt lost his left hand on December 23rd of 1985 in an accidental fireworks explosion while he and friends were celebrating the holidays. Although the accident was deeply traumatic, Matt went back to work as a paramedic the next fall. Matt reported his healing process as difficult emotionally and laborious, saying shortly after the accident "[I was] absolutely convinced that my life as I knew it was over. I was never going to be a medic again. I was probably going to end up on a street corner, selling pencils or something like that, that typical thing. I absolutely believed

that in the beginning." Friends and family were crucial to his eventual transition back into a regular schedule of work and life. Matt says, "As time moved ahead and the people around me were encouraging and working with me and helping me to rationalize and figure out things—and as things became more evident that I *could*—I think the idea that I *couldn't* just became further and further from my psyche. It was more of, 'Now, how can I get back?' as opposed to, 'What am I going to do to get back?' I knew what I had to do, and I just went out and did it."

Navigating personal relationships was described by Matt to be, in some ways, more daunting: "I was a young guy. I was 24 years old. The idea of dating and things like that with a hook… I thought, 'that's a horrible thing to think,' but it's what I was thinking when I was that age. I did have that period of depression, but once the prosthesis came, and I saw it was cosmetic, by and large, in its appearance, and it opened and closed, and once I learned how to use it and once I got fairly adapted and adept with it, things started to look a little bit better." Matt says his Otto Bock prosthetic hand "worked well," but nevertheless did *not* feel to Matt that it was ever an adequate substitute for the real thing. Matt reports the prosthetic was uncomfortable and annoying (he had to have a spare battery with him at all times and to check the device's charge consistently throughout the day). He also remarks that it was unbalanced and heavy, causing occasional pressure sores "and things like that."

Eventually, Matt says, he was "successful in all the ways we define success." But the feeling of otherness and loss did not disperse over time. Instead, he says, it was the opposite: "When I would meet people, I would position myself where my prosthesis was out of their view. I would turn my body so that they couldn't see that. Until some point in time when ... they would finally realize that, then I have to explain my life to them and what happened and how I did this. It just became a very tedious and angering-type way of living." The cumulative effect of these

negative social interactions made life difficult to enjoy on a daily basis. “Inside, no, I wasn’t happy,” Matt says. “I was probably more angry than anything. As the years went on, I became more and more angry. Of course, the anger was inward, but sometimes I directed it outward, and was sometimes harsh at times with people, not because of their shortcomings but because I was angry with myself.”

It was many years after Matt’s accident that hand transplants began to be seriously considered by doctors as a possible solution to chronic disability of the upper extremity. Matt remembers clearly the day he heard about hand transplantation:

> I was in London, England, in all places. I was over there on a little bit of vacation. On the day that we were leaving, my dad’s wife came upstairs. She went down to the coffee shop and came upstairs with the newspaper and said, “You’re not going to believe this.” I said, “What’s that?” She showed me this article in the Sunday London Times, I’m pretty sure that’s what it was, about this hand transplant team in Louisville, Kentucky. Now, I’m in London, England. I’ve been in the United States, I didn’t hear a word about it. I had to go to London to hear about it. It was a big, two-page article. I read it, read it again on the plane ride home, and the next morning, after waking up, I called Jewish Hospital in Louisville, Kentucky and said, “I want to be part of this.”

Hand transplants were an entirely new option at the time and there was no guarantee a biological hand graft would be as functional as Matt’s Otto Bock prosthetic. Matt says he was well aware of the risks of participation, “My wife at the time was a registered nurse. I was a paramedic. It’s not like we had to learn a whole lot in the way of things, I mean, other than the specifics of transplantation, but I understood the pharmacology. I understood the problems that are going to

happen. I understood [much of the science of] rejection." Still, Matt had to seriously consider the many potential complications and sources of pain associated with hand transplantation (including physical and cognitive side effects of immunosuppression, disruption of life during a long healing period, intense post-care treatment, pain, and the constant possibility of graft loss).

In our interview for the oral history project, Matt describes the hand transplant as a needed intervention conferring not functional restoration but what might be termed narrative transformation. From the moment he woke up with the graft hand, this element of healing from a long-time psychological wound was present:

> When I woke up from the surgery the first time and I looked to my left, my hand was gone. It was wrapped up in all these bandages. There was a little bit of Betadine, maybe a little bit of bloody drainage there, but the hand was gone. This time I woke up and looked to the left and there's fingers pointing at me. It was like it was almost a replay of that waking up in the recovery room 13 years prior. It was very weird. Yeah, it was very weird… [The hand] was very heavily bandaged and everything, and I see this index finger and middle finger and ring finger pointing out at me and I'm like, "Oh, my God!" It was just the strangest, strangest feeling of like, "I've been here before,"—but the outcome was different. Instead of it being gone, it was now back.

After the hand transplant (and a great deal of media coverage of it), the putatively negative—and, for Matt, experientially negative—labels "amputee" and "disabled" could no longer be associated with his identity. The positive valuations people seemed to make of Matt after learning of his participation in a "miraculous" groundbreaking surgical experiment made a conspicuous difference in the way that Matt perceived his own value, particularly as reflected in

the eyes of others. The hand transplant also conferred some advantages in terms of function and aesthetic restoration—however these have never been the focus of Matt's reflections on his experiences.

Years after his transplant, Matt met his donor family to thank them for their gift and says he feels nothing but gratitude for the opportunity to participate, stating that, "If it fell off tomorrow, I'd do it again. I feel like I've been healed in a way that would make another amputation far easier than the first one."

Narrative 2: Rich and Cindy Edwards

One night in February 2006, a chiropractor from Oklahoma was driving to a hunting trip with friends when a brush fire completely overwhelmed his truck. On trying to escape the flaming vehicle, Rich's hands were severely burned, and healed into claw-like stumps that Rich called "deranged looking." Before the accident, Rich had been a well-respected chiropractor with a busy practice in his hometown. He had to quit working at his practice and suffered extreme depression as a result of his injury. Rich recalls:

> "I lost most of my fingers, 7 of my fingers [in the fire]. My hands were distorted, and contorted, but I was still somehow determined that I was going back in to practice. That set in depression, for the first time in my life. I was extremely depressed for years… I still had hope that I could find somebody who could fix my hands, get them limber, and movable again, instead of clenched up into kind of a fist. We found what, we thought, was the most outstanding one, which was at Duke University. He did 5 or 6 surgeries, and my hand was actually worse off than it was before he even started. I was very unhappy about that."

After disheartening experiences with traditional reconstructive methods, Rich and his wife, Cindy, turned to doctors in Louisville, Kentucky to discuss hand transplantation. Rich had never tried prosthetics, and prosthetic rejection had been a stipulation of candidacy in the early years of the Louisville hand transplant program; however the lead surgeon at the time of their consultation, Dr. Breidenbach, thought Rich might attain better-than-average results due to the fact that his hands had never been amputated, and some length of the existing nerves could potentially be preserved and transplanted into the graft hand, reducing the amount of time for recovery following transplant. Although Rich was initially rejected as a candidate by the first psychiatrist in Louisville, he was eventually reevaluated and approved for transplantation.

Unfortunately, Rich's desire was not to regain *some* function from his new hands, (which was likely), but to regain enough function to be able return to his chiropractic practice (which was not). Transplanted hands do not work as well as a "normal" hand; even an excellent outcome with a hand graft will never attain the same level of dexterity, sensation, and strength as the original. It may have been a collectively conditioned response, or an indication of the importance of understanding the limitations of these surgeries, that when I first began researching hand transplants in 2010, almost every member of the team I interviewed in Louisville observed, "Our patients aren't going to be concert pianists, you know."

As years passed post-transplant, it became more and more clear to Rich and Cindy that the much-desired result of returning to work after hand transplantation would remain out of reach, and Rich's depression again became debilitating. While experiencing some return of function and sensation *was* deeply meaningful to Rich and Cindy (for example, being able to hold hands together and to pray, more bathroom autonomy, among other affordances), his spirits continued to plunge. At the end of the summer 2015, Rich visited a shooting range near his home and killed

himself. Cindy mourns the loss of her life partner and is conflicted when describing whether she thought hand transplantation had been the best option for their family.

> "Rich couldn't live like this, like the way it was [after the fire]. People were always staring at his hands. Children were always staring and pointing. Even though he can't do hardly anything with his hands right now, at least they look mostly normal… I don't recall really hoping that he'd go back to practice or believing that he would. He did. He was hoping and believing. I didn't necessarily bank on that, but I was hoping he be able to go back emotionally into the practice. We had an associate doctor that was carrying the practice for us while he ... After our accident, we had to hire a doctor to carry on the practice. I thought, 'Well, if he could go back in and just oversee and work with the patients and all this, even if he couldn't put his hands on them and adjust…' That was my hope for him, but, because he *physically* couldn't do it, emotionally and mentally, he just actually was defeated. He was just defeated by it and didn't want anything to do with the practice, didn't want to go back in if he couldn't do it. He pretty much didn't want anything to do with it. That was hard. That was an expectation that we never achieved. I was also hoping that he would be able to do more with his hands, and he just can't. He just can't do more. I mean, he can't. They told us he wouldn't be able to button buttons. Okay, I accept that, but he just won't… I wish, just sometimes, just very, very little, that Rich would have prosthetics instead because, then, he wouldn't have to take all those medications."

Rich's death was not widely reported in the media, and there has not been, to my knowledge, a clinical case report published on Rich's outcomes. While suicide approximately five

years after a self-styled "life-enhancing" operation may not look like success to some, Cindy has stressed repeatedly in interviews that the hand transplant was better than no change at all.

Intriguing to me, in conversations with Rich and Cindy, both partners have mentioned a shift in their values regarding healthcare which was both necessitated and facilitated by the hand transplant process. Before the accident, Rich and Cindy said, they were: "Chiropractic, not medical." Both partners were suspicious of medicalized tendencies toward unnecessary high-tech intervention, and both believed in the power of the mind or spirit to heal the body. Rich had even been dismissive of people claiming to suffer depression in the past (an attitude he regrets following his own experiences). For all of the above reasons, Rich and Cindy were not organ donors. Their philosophy of health and medicine changed greatly after the hand transplant experience. First, the high level of compliance and cooperation necessitated by hand transplant recovery made it necessary to "buy in" to traditional western medical values of transformation and scientific progress—this was not, they reported, difficult as the hand transplant was such a unique, exciting, and emotionally moving prospect. Second, the extraordinary "gift" of the hands elicited feelings of wanting to reciprocate, and persuaded them of the value of other types of transplants—both Rich and Cindy quickly became strong advocates of organ transplantation and donation, and Cindy donated Rich's hand grafts to medical research after his death.

Narrative 3: Angel Gonzales and Will Lautzenheiser

Double hand transplant patient and former quadruple amputee Will Lautzenheiser was an early-career professor of filmmaking in Boston before a virulent streptococcus infection in fall 2011 necessitated amputations of all four of his limbs. Will's recovery process included noting and critiquing the ways in which socialized expectations and aesthetic ideologies seemed to mediate his experience of disability in public spaces. Will also found solace in humor: as a former

English major, Will enjoys laughing about the inescapable presence of hand metaphors in the English language and has even performed standup comedy in which his jokes often moved toward the tension of his appearance by acknowledging and commenting on his experiences as an amputee.

Will's partner, Angel Gonzales, is a thoughtful and reflective Brooklyn native of intimidating self-knowledge, with an apparent talent for nurturing peace and health in challenging circumstances. Will and Angel had been dating for a less than two years before Will's sudden illness and the amputations that followed from it. Angel stayed to help Will through the healing process, and describes the decision as second nature: "I'm not ... *interested* in running away; I'm interested in the difficult aspects, if that makes sense. The difficult to me is more interesting. That's...more of my character."

Will and Angel worked through months and years of readjustment involving prosthetics, care assistance, and modifications to their apartment allowing Will to perform a range of daily tasks for himself. Life had attained a degree of normalcy when doctors in their hometown of Boston offered Will the opportunity to participate in an experimental double hand transplant. Angel describes his reaction to the offer as mixed, and in some ways he was bluntly skeptical. Growing up in Brooklyn, Angel says, he was immediately looking for the "catch" and describes his reservations:

> For all purposes [Will was] was *healthy*, he just didn't have arms and legs. So these medications introduced a whole new set of things that might happen which will not necessarily facilitate *life*. You know, the skin cancers, diabetes, you know all kinds of maybe kidney problems—so in that sense I'm like, "You really need to consider

this." And, I kind of, wasn't just, jumping on *board* with it, but, I was also not gonna say, "Well you can't have *arms*" you know; I wanted it to be his decision.

Will received a double hand transplant in October 2014. In the recovery period, Will and Angel worked diligently to keep the hand grafts healthy. Their daily schedule, and many aspects of their life together, had to change following surgery. Of special concern to the couple was the temporary loss of all their work finding some equilibrium at home between Will's needs and Angel's ability to offer care, since Will's hands would be in hard casts for months, and then useless "dead weights" while the nerves slowly regenerated (function for hand grafts and hand replants returns slowly as nerves regrow, about a millimeter per day). Fortunately, the double hand transplant has not been a problematic development as Angel once worried; rather, the couple reports being truly delighted by the new hands, even before they were functional.

Both Angel and Will use the analogy of caring for an infant to describe the early period of living with the hand transplant. Angel said of this time that they were constantly on guard for signs of infection and rejection, but that the excitement of their new situation and its potential made the uncertainty more bearable:

> To me it was, I guess, the closest I'll ever be to ...having *a child*? So it was kind of like, these sort of instinctual things come with it ... you know [with a hand transplant] some people suffer from pain and, you know, stay up all night so, [Will's transplant hands] were very *quiet* babies. [Laughs.] So um, it kind of, it came natural, in that sense? It didn't seem foreign, you know what I mean, that I could *help them along* and try to kind of, discover or, figure out, *together* what would be best and how we could help the arms grow. It wasn't so much like, "this is where you know you can sense your feelings and what can we expect," just we're

> constantly watching them ... I think when Will has fully regained sensation, or *if* he fully regains sensation, uh, and proprioception—so that he doesn't have to think about where his arms are—that will be the sort of, the day that the baby's grown up!

In a similar vein to the undetermined sense of value and development that Will and Angel placed on the hand grafts, Will describes the process of coming to know or fully own his new hands as one of watchful awareness of emerging significance. Morphologically, Will's transplanted hands have undergone subtle aesthetic transformations, and these alterations of form and function have been the focus of much semiotic speculation. He describes a pattern of continuous discernment early on in which he was attempting to differentiate between the physical qualities of his hands that might be consequences of his own actions and care, versus those that may be from the lifestyle of his donor, versus those that might indicate underlying biological processes (including signs of rejection and infection). Will describes his experiences of coming to "own" his new hands as an emotional and rewarding learning process:

> I have a couple of scars that weren't things I had earned. I saw them on the hands, and I thought, "Well, that's fascinating. I wonder how my donor acquired them." Everyone has scars on their hands, but generally, you know where you got them. You've got stories related to them, and this is one of these weird cases where I literally don't know where my hands have been, which is funny.
>
> When I was in Phoenix [giving a talk for a transplant conference], I unwittingly learned a lot about my donor, because I was talking as part of a panel that presented this donor case, and I was a patient sort of representing one of the beneficiaries. This donor actually benefited 10 different people with 11 different organs ... One

thing I learned is that my donor practiced karate, and I only imagine that maybe some of the scars that came, I think some of the scars that came around his hands must be from that. I don't know, of course, but it's possible.

There's an interesting transition. Several weeks after, I noticed, of course, that the hands were rough, were calloused, and I noticed several weeks after my transplant, I was home for a while, that the skin began to slough off my hands. The callouses began to wear away, basically. The skin underneath was sort of fresh and pink and soft and all this ... There are ways that you can build strong hands, and build callouses up on your hands, and whether [my donor] did that or not, I don't know. But that work was going away, and it was represented in a more—not necessarily the hands of an academic, because my hands weren't all that soft, I don't think—I don't know. I took that as a, "It's okay. It's all right for me to think of these as mine."

At the same time, of course, I can't feel everything in them yet, and the nerves are only slowly going down, and I don't have total appropriation in them. There's a lot about them that still feels not quite mine. I don't think I'll ever lose—as much as they feel increasingly like mine—I don't think I'll ever lose the sense that, in a way, I owe something to someone with them. I don't think that's a bad thing. That's not negative. It just makes me realize, it's a reminder that I need to be grateful, and not just for this. I'm happy with that.

Narrative 4: Dave and Karen Savage

Dave and Karen Savage live in Bay City, Michigan, near where Dave grew up, and where they both enjoy residing in close proximity to their extended family and adult children. Dave describes his childhood in Michigan as peaceful and enjoyable, drawing (for emphasis) an implicit

comparison between the values characterizing those simpler times and our contemporary landscape: “Back then it was easy growing up. You went around, did whatever you wanted to do—if you wanted to go out, there was nobody lurking around in the shadows, ya know? It was a *good* time.”

Dave and Karen met in their 30’s after they had both been married with kids of their own, and long after Dave suffered a traumatic injury to his dominant right hand in a machine press accident. Dave, a quiet person whose economical style of speaking leaves some work to the listener’s imagination, describes the accident as a “plain and simple” event resulting from the confluence of two factors. The first factor Dave characterizes as material or environmental insofar as, “some of the devices that were there for safety just weren’t on the machine,”—a fact both Dave and the corporate insurers who covered the accident attributed to oversights by the company Dave continued to work for the rest of his professional career. The second factor Dave narrates as his own failings of attention and knowledge at the time, “You’re young and you’ve got a job and …ya know, there are safety rules that are involved in it and you don’t know ‘em all.”

At the time of the accident, Dave knew immediately that his hand would have to be amputated. Dave says, “[the machine press] just smashed it … You could tell [my hand was unsalvageable] just by looking at it.” Although Dave (like many narrators) uses second person when recalling many events, including the loss of his hand, he recounts the time period directly after the injury in first-person terms, emphasizing (somewhat surprisingly to me) the lack of disruption to his life that the loss represented and his own agency in managing his post-traumatic experiences. Dave says:

> “When I woke up after the surgery, first thing is my wife was standing there with my draft notice. Uh, so if that would’ve came a day earlier, the accident would’ve

never happened because I wouldn't've went to work. But then, I looked around and I seen where I was at and I said, 'I ain't staying here.' So, ya know, I worked a deal to get out of there and all I needed was a pair of shoes. So my father-in-law lent me his shoes and I got up and walked out and went to the other hospital… Um, like I said it's hard to explain. I lost [my hand] in an industrial accident and uh, life went on from there!"

Dave also revealed his humor in this bit of narration. I asked him what inspired his decision to switch hospitals following such a major, seemingly traumatic surgery, and he said:

DS: They couldn't put me in a private or semi-private room. They put me in a twenty bed *ward*. And everybody was in that ward from crazy people on up. So, I didn't wanna be there.

EH: *Ok, and how long were you in the second hospital?*

DS: The second hospital? Oh, gosh I dunno probably about two weeks, maybe.

EH: *Wow, and that was just caring for the wound itself or did you receive other types of treatment?*

DS: Yeah, it was just caring for the wound, waiting for all the swelling to go down, stuff like that, ya know—the other reason I wanted to go to that hospital is 'cause my mother worked in the kitchen.

EH: *Nice.*

DS: So I knew I'd eat good. (Laughing)

Dave describes life post-amputation as being much the same as life before, with a few modifications. At the time of his injury, Dave's first wife was pregnant; although he does not

indicate this special family status as a reason for wanting to return to work, he says that the loss of his hand did not diminish his ability to do so, "I might've been off work seven, eight months at the most? I was going crazy—I *wanted* to go back to work. When they called me and asked me if I'd come back to work, I didn't even hesitate. I didn't even have my prosthetic yet, when I went back to work."

When Dave and Karen met in the mid-80's, Dave was still using a simple cable hook prosthetic to help manage daily tasks. He says of the device that, "sometimes it helped [and] sometimes it got in the way." Dave and Karen both observed that the serious limitations of using the hook when interacting with other people was the most frustrating aspect of its manifestation as a "replacement" for his lost hand. Sometimes these interactions were upsetting and isolating. Karen describes the feeling in sharp recollection: "Dave helped me get off the ground a youth football program, and he was one of the coaches. Our son [Gus] did a lot of the demonstrations …because Dave couldn't throw a football, or catch the ball in a way the kids would be instructed to catch it. … That bothered him because he was there to be a coach and be there to help them, and I think it bothered him a lot that the kids would shy away."

Although Dave was an amputee for over 30 years before having the opportunity to participate in hand transplantation, the long period of posttraumatic recovery and adjustment did little to diminish his interest in being made whole again through some kind of intervention. "[Dave] never wanted to think of himself as being handicapped," says Karen. However, the loss never felt justified, and it was hard to fully accept. Karen says, "If certain safety factors would have been enforced—if the company would've done what it should've done to guarantee all their workers' safety—this probably never would've happened to him. I think anybody would resent having been

pushed into working in a situation that wasn't safe and now he's got to deal with it the rest of his life."

Dave never stopped thinking that someday—not supernaturally, but possibly within his lifetime—he would have two hands again. He believed in the power of science to provide a path to restoration. Dave says, "like one guy was trying to figure out why certain animals could grow their limbs back. Ya know? And thinking they could apply that to humans, and I dunno whatever became of that." Karen remembers exactly when that distant possibility became a close reality:

> "Dave was pretty functional, but ever since day one with me, he always said, 'If there's another way to get another hand, I'm going to try it.' We joked about the idea that, yeah when we get to heaven, we're going to have perfect bodies, God is going to give us perfect bodies, and you'll have your hand back, and I'll be skinny, and we would make a joke about it. That's kind of how it was with us from the beginning. Then, one night on TV they had an article about Matthew Scott and his hand transplant, and I saw that and I looked at Dave and his eyes were like, 'Wow—I have to check on this,' and he said to me, 'How will we ever find out about this guy? How do we do that?'"

The next day, Karen says, she, "got busy with the TV, with local newspapers, and got a contact information for the person who did the interviews, and then that person that did the interviews gave us contact information for the hand transplant program in Louisville." After a long period of evaluation and negotiation with the insurance company that covered his initial accident, Dave was listed as an experimental patient for the Louisville hand transplant program. Jewish Hospital, which hosts the program, agreed to cover all costs except the follow-up immunosuppression, which Dave would have to take for the rest of his life. Karen describes the

exciting decision to try for the hand transplant as being heavily mediated by reminders of what could happen if the transplant went badly:

> "[The doctors] wanted us to be totally aware of what it would do, what it possibly could do. It was a big concern to the point of, 'Maybe we shouldn't do this'—because maybe all these drugs are going to hurt you in the long run, and there won't the benefit we're expecting out of the transplant. The other part of it, when you think about it, is hand transplantations—if a person's going in, and they're having liver, or heart, or lung transplants, you've got to have that to live. A hand transplant is something you're going to have to improve your quality of life, but you can get along without it."

Dave and Karen waited what seemed to them a long time for a hand graft to become available. Dave says he waited through, "like four false alarms there" which were stressful and discouraging. However, after the a match was made and the transplant surgery accomplished, Dave and Karen both describe being amazed by their instant affiliation with the new hand. Dave again emphasizes a feeling of continuity or normalcy rather surprise or transformation on waking up after surgery: "I didn't feel any different. I looked down and I saw it there, and right away ... everything was mine! Ya know and as far as my wife she felt the same way!" Karen agrees, "It was immediately his hand."

For many years, the transplant conferred both functional and psychosocial benefits, sufficient to be worth the work and effort needed to maintain it. Dave says, "when you first get [a hand graft] you know it's all great and you know, you put all this hard work in with the physical therapy and all that … at first everything was great!" However, minor complications and difficulty

managing transplant drugs caused more and more stress and discomfort as the years went by. From Karen's point of view, the changes to their quality of life were not always good ones:

ER: *How did life change after the transplant?*

KS: He's grumpier.

ER: *Really?*

KS: Yep. A lot of times he's not feeling really good. I tend to blame it on the medicine.

ER: *Was it like that from the very beginning?*

KS: Let's see. It's kind of hard for me to say because at first, when he first had the surgery, you got your surgery recovery time. You know, where you're not feeling good because you just had surgery, and all this stuff is healing up, plus he's on all the new medicine where he doesn't feel good because his stomach's upset from taking all this medicine. That lasts a long time. Once the hand starts looking better, and he starts feeling better, it kind of eases up, but it never goes away.

Dave acknowledges that there were numerous challenges. In managed complication after managed complication, he discovered firsthand that high levels of immunosuppression would protect the graft hand but harm his own health, and vice versa. By the time of our oral history interview approximately ten years after his transplant surgery, Dave was easily animated when talking about the long-term challenges of hand transplantation, especially in terms of post-transplant medications:

"[At one point] they changed [all of my drugs]. Uh, I started out with Prograf and Cellcept? Something like that, and since then, they've taken me off Cellcept and

they put me on what's-it-called, Rapamune. And of course the Rapamune does the exact same thing that the Prograf does. So they had me taking both of them at the same time, and in the meantime the Prograf is screwing my kidneys up, and uh—so now they've taken me off the Prograf, and now I'm on a drug they call Myfortik. And I take that four times a day. And then I take Rapamune. Ya know uh it's two milligrams a day. And I'm still on the steroids. And I was supposed to be well *off* the steroids."

Despite a long period of satisfaction in which doing small hobbies and having a human hand again conferred high satisfaction, over time the deteriorating quality of his clinical relationships, personal health, and the graft itself have soured Dave's experience. He described several times throughout our interview the frustration that came with not knowing why his drug regimen was being changed or why doctors wanted to do a particular procedure:

"I mean they've been doing this off and on throughout the whole, whole thing! Ya know they'd call up and they'd change [my drugs], and uh, say you were gonna go I for surgery or something. They'd have you stop taking a certain drug and go back on the other drug, ya know 'cause one drug slows down the healing process. Ya know and this is what I've been trying to tell 'em about [my damaged, bleeding] fingertips! Ya know you've got me on a drug that slows down the healing process! Can you just take me off that and put me on something else for a while? And ya know it's just like—I get no response. That's my biggest frustration: I get no *response*. … It got so bad, that I went down there in June, and when we sat down to talk, the first words out of my mouth I told them, 'I am ready for it to come *off*.'

> Annd I think it just shocked them. 'Cause all the sudden they wanted to do this, and they wanted to do that."

Because Dave's hand transplant came as part of a research grant and his continued care is covered under Louisville's funding, if Dave wants a second opinion at another institution, he has to pay for it out of pocket (which he can't do). The experientially *proprietary* nature of Dave's relationship with the Louisville program has thus been a major source of dissatisfaction with the hand graft that has little to do with the phenomenology of the hand, itself (about which Dave still has positive feelings). Dave says, "I really am I am very frustrated. 'Cause I feel I'm getting no—I, I feel like I'm going backwards. You know what I'm saying?"

While a few of the doctors who brought Dave into the Louisville study remain there, most have gone on to start new reconstructive transplant programs at other institutions. As we talked, it seemed to me that deteriorating clinical relationships were as much a source of stress for Dave and Karen as the complications of the hand transplant aftercare (which include, for them, yearly trips to Kentucky for checkups, and winters spent in an RV in Arizona to protect the hand graft from the cold). Dave frequently compared his (more positive) experience working with the doctors on the original Louisville team to that of his experiences working with newer, in his opinion more aggressively experimental, doctors. Karen has a similar outlook:

> "The treatment that Dave got at that beginning, right after his surgery with that particular team of doctors and nurses was most excellent. You couldn't ask for a better group of people. As time has gone by, a couple of the doctors have left the program, and each time one of the doctors leave … Each time one of the doctors leaves, the new doctors coming on board, it seems like they don't have the ownership of the program that the previous doctor did."

Ultimately, Karen says, she would not want Dave to choose the hand transplant if given the choice to make over again. At this time, Dave still has his hand graft although the function and appearance of the hand have gone down dramatically. He says, "if I could work my hand, the way I *should* be working it, I could probably get 50-55 percent function out of it. Ya know, but the way it sits right now, basically all I can do is hold something between my thumb and finger. My index finger. That's it! Somebody hands me a receipt I can grab it—well heck, I could do that with a hook!"

It is unclear what kind of exit strategy has been prepared for Dave and Karen by the Louisville hand transplant team. Although Dave's hand graft has been described as in a state of non-salvageable, slowly progressing "chronic rejection," and although he has been recently diagnosed with metastatic squamous cell carcinoma,[1] diabetes and kidney problems that are complicated by his immunosuppression, Dave is deeply conflicted about the idea of losing the hand graft. In scientific presentations to the VCA community, Dave's doctors say that they want to respect his wishes in terms of keeping the graft as long as possible because "he is attached to it."

Narrative 5: Vasyly Rohovvy

Vasyly Rohovvy is a bilateral hand transplant recipient currently living in Austria, although he is originally from Ukraine and was living in Ukraine when an accidental blast injury resulted in the loss of his eyesight and both hands. When I interviewed Vasyly, he was visiting the University of Pittsburgh for a conference on eye transplantation; his sister and personal caregiver,

[1] As reported by Louisville team member Tuna Ozyurekoglu on Thursday, November 15th 2018 at the 6th biennial American Society for Reconstructive Transplantation (ASRT) meeting: http://www.a-s-r-t.com/2final2018MeetingProgramScheduleweb.pdf; confirmed via email 27 November 2018.

Elena, was traveling with him. Vasyly wore dark glasses as we sat on a patio near the Cathedral of Learning in Oakland. He was cheerful, having been a keynote speaker at the conference the night before, and spoke excellent English with a strong Slavic accent.

Vasyly considers himself a lucky person despite the many considerable challenges he has faced. He says he had a "very happy childhood" which he attributes to a lack of access to drugs and alcohol on the streets in the USSR when he was growing up. Nevertheless, Vasyly understands that, "there was disadvantages and advantages, so to say, in USSR. For children it was a good childhood," he says. "For my parents it was not so good, because, I don't know how to say… In that time, they say that there was no freedom. I don't know what does it mean, 'freedom.' There was no slavery, but I don't know. My father was happy, so to say, when USSR fall. My mother was not happy."

The accident occurred when Vasyly was eighteen years old and studying IT. He describes the event:

> "I was going home with my dog and about 600 meters from my home I saw a car and inside the car I saw a bag. I saw that someone had forgotten it. I wanted to find out what it is in that bag, if it's money. I stopped and picked it up and I tried to open it. That didn't work and then I yanked harder. I lost my eyesight on the spot. I couldn't realize, of course, what happened to me. I tried to rub my eyes and only then I understood that I have no hands. I was scared and I ran to my home, looking for help, but I took a wrong direction. I ran to another side, so to say. I ran and hit cars, walls, trees, I don't know what else, and fell down and stand up, but because so big blood lost, after the next fall I couldn't stand up anymore. I was lying on my

back and thought that I was dying, but suddenly something in my head began to scream, ‘Call for help, do something, don't sleep!’”

Vasyly says that the snow on the ground that day helped the ambulance to find him quickly after a bystander dialed for emergency help. A week later, Vasyly’s parents rented a car and took him from his hometown to Kiev (about 300 kilometers away). At that time, doctors were able to save his right eye, but nevertheless, Vasyly says, “I didn’t want to live. I didn't know how to live without hands, with burned face, with very poor eyesight. I stayed at home by myself and didn't want to see anybody.” Vasyly’s sister, Elena, was instrumental to his recovery via hand transplantation, “My sister started looking for clinic that could help me. She went to the internet café and she looked for a clinic that can get my hands back, so to say. In a few months she found in an article about the hand transplantation in France. We found a teacher and she helped us to translate a letter from Russian to French and we sent that letter to France, Lyon.”

After Vasyly and his family identified hand transplantation as a potential route to to restoration, they negotiated with programs in several different countries to achieve candidacy. He describes the process of evaluation and waiting for a hand:

“Of course, it wasn't possible for us to get an appointment [in Lyon, not being] a resident. We tried to do it, to find money ourselves, but the French doctor didn't want money, they want involvement of Ukraine government. We couldn't do that and after that my sister found a clinic in Germany, in Munich. We went to that clinic, I passed all medical checkups. It was 3 years after the explosion. I didn't have German citizenship and therefore they couldn't find money for surgery. I was waiting for the answer about 2 years from Germany. They didn't answer to us and my sister went once again to Germany and took all my all medical results and

> brought them to home. She found another clinic in Austria in Innsbruck. We sent a letter to the director of the clinic in Innsbruck. He answered us and said we can come to Austria, to Innsbruck. In 4 months in 2005, my sister and I came to Innsbruck. I passed all medical checkups once again and then was waiting for the results… About 11 months I waited for a donor and in May 2006 I received a call from the clinic that they have hands for me and after that I was 17 hours in surgery."

Vasyly knew that the hand transplant would mean that his life "will be forever connected with my doctors and with the clinic." He describes himself as being a tireless worker for the health and functionality of his hand grafts and an eager participant in the process, despite the downsides of taking transplant drugs: "After the hand transplant I did the therapy, every day from Monday to Friday from 8am till 5pm. I take immunosuppressants and there are a few side effects."

Vasyly had severe phantom pain after the explosion, which fortunately resolved after the hand transplant. Although his eyesight is now totally gone following complications in a repair attempt, Vasyly says that the aesthetic, human appearance of his new hands is highly valuable to him. "I was very afraid that I will get big hands. I asked my doctors to find for me good hands. I had very long fingers … I asked my sister, as I said, to tell me how do they look like and she said 'No worries, they fit you perfectly.'" His function is also good following extended efforts in the hand therapy clinic in Innsbruck: "I did the therapy for 3 years. I know there is very few patients who did therapy for so long as me. I learned a lot of things that I took for granted before the explosion. To eat. I had to relearn everything, to dress myself, to eat with fork, spoon, to open a bottle."

Although early on the management of transplant medications was difficult, insofar as, "It was very difficult to take a lot of pills—about 20, 25 pills. Of course, I felt sick." However, Vasyly

says that, “nowadays I take 3 pills in the morning and 3 pills in the evening” which is very manageable. The special advantages of hands over prosthetics are clear to Vasyly. “Feeling sensation is very important for me, because if you cannot see, you only have one connection with the world. Fortunately, my hands can feel rain, sun, wind and I can feel almost human being if I touch your hand, I can tell—I feel.” At this point Vasyly invited me to test his sense of touch and sensation. I reached out to shake his hand. “Your hands are a little bit cold... Cold finger as I imagine.” He was right, my hands are often cold.

Nevertheless, Vasyly reminded even at the end of our interview that, “Hand transplant, it is not a miracle. [I knew] I will not get my old hands. I will get new hands and these hands will cause pain, there is a lot of work to do and a lot of things depends on me, not on my parents or on my doctors, only on me.” One aspect Vasyly discussed at length is the idea of reasonable expectations as a factor to success. “I didn't have very big expectations. Therefore, I wasn't disappointed. Before the hand transplantation I met other hand transplantation patients. I saw what they can do with their hands and I talked to them. I think it's very important for everyone who wants to get new hands to talk to people who already have them.” Vasyly has gone on to marry a woman he knew before his injury, has a daughter, and continues to receive some day-to-day care from his sister Elena.

Vasyly recognizes that aspects of his life have been extraordinary, where his hand transplant experiences represent a necessity for his welfare and hard work. “We were just an ordinary family from Ukraine. [My doctors] told me I had only one solution, they told me that don't give up, one day you will get your hands.” But no amount of relevant preparation, he emphasizes, can ensure success with a hand trasnplant. Vasyly says, “I'm very lucky.”

Narrative 6: Sheila Advento

"We all have meningococcal agents at the back of our throats, as I understand it," says Sheila Advento, trying to describe the source of a viral infection that, several years ago, almost killed her. Although meningococcemia is non-threatening among people with a healthy immune system, for some reason, Sheila was susceptible at that time, and from what she thought was an average cold or flu, her health deteriorated rapidly. By the time Sheila was rushed to the hospital for acute nausea and fatigue, she was gasping for air and had to be induced into a medical coma to save her major organs from failure. Unfortunately, the illness resulted in severe necrosis of all four of Sheila's limbs, and she left the hospital a quadruple amputee.

Sheila Advento was born in the Philippines but came to the United States as a young child. The potentially disruptive or disorienting immigration experience was mitigated by early introduction to American culture via school. Sheila says, "Maybe a month after arrival, I went to school right away, so I got adjusted almost immediately." Plus, "It's mandatory that we learn English in my country, as well as any other country really. We watched a lot American movies and stuff."

Sheila was an independent person supporting herself and going to school before she got sick. It was difficult to transition to a life where all of her personal needs had to be met by another human:

> "I cried a few times, but I was also under antidepressants, so that helped me. I was in the hospital and then also I was in rehab. Especially when I was in rehab, I felt like I was confined in secure place, in a secure bubble. Where they do the exercises, occupational therapy, physical therapy, and doing things that I eventually got accustomed to and knew what to do because I was in this bubble. It wasn't until I

was discharged that things started clicking, how difficult life is as an amputee. I was getting really depressed, and I didn't know how to handle things emotionally. I was frustrated a lot, I took it out on people. I didn't know how to calculate the frustration into my life. I didn't know how to handle anything. I just wanted to be independent, and it was hard to ask for help, is was *so hard* to accept help. I didn't want to pity myself, I didn't want anyone to pity me. It was all these heightened emotions that I'm not familiar with that just came into the picture. … [Before], I did everything on my own. I got dressed on my own, I did my makeup and my hair on my own, did the laundry on my own. Then all of a sudden all that's gone."

Eventually, Sheila and her family hired a personal assistant, but things started looking up especially after Sheila came across an article about hand transplantation. Sheila says, "I reached out to the facility. I reached Dr. Lee, who was there at that time. He almost immediately responded back. I sent him pictures, and we just exchanged communication to the point where I was invited to do the screening."

Compared to other narrators on this project, Sheila's evaluation and waiting period for hand transplantation were rather fast (completed within a year):

"For about a week I did all the necessary screening process that they required. That includes psychological testing, a lot of blood work, seeing multiple doctors, and meeting with a transplant team. Then eventually, it wasn't that long after, I got approved for a transplantation. I thought that I may have to wait years. That was a reality I was thinking about, that I would have to wait years for a donor. had a safety bag on the side, just in case [and] I only waited nine months. I remember I actually had a day off of work and I was just watching TV. I got a call and I was told that I

needed to travel right away, because I had a donor waiting, so my mother and I traveled to Pittsburgh. We took a plane to Pittsburgh."

At the time of our interview, Sheila was completely satisfied with her experiences as a hand transplant recipient. Despite what she describes as a "grueling" the post-operative therapy and medication regimen as well as some debilitatingly severe headaches in the early phase, Sheila described her experiences in positive terms, emphasizing the gradual return of function and sensation in her hands as a thrilling and pleasurable, unfolding experience. "I'm able to do so much more. It's exciting for me. For instance, I'm able to grab somebody's arm, I'm able to hold somebody's hand, I'm able to hold my boyfriend's hand. It's a nice feeling. Not having hands, eventually you lose the intimate feeling… I feel like my sensations are back. It's just very exciting. Everything is so exciting for me."

As part of my evolving oral history protocol, I asked as one of my final questions for narrators how their relationship with their clinical providers has evolved over time. At the time of our interview Sheila Advento was happy with her outcomes and with the quality of her care from the team at UPMC (although by the time of our interview the program had migrated to Johns Hopkins University). However, as recently as November 2018, one of the lead surgeons on Sheila's team has reported that Sheila is in renal failure and in need of a kidney transplant. He also admitted that Sheila is now seeking care outside of their program (Shores et al, American Society for Reconstructive Transplantation, Chicago 2018). Sheila attended the meeting where these results were presented; however, she was not invited to speak publicly about her experiences. She did personally confirm this distressing, ongoing outcome to others and her lost faith in the transplant team at UPMC/Johns Hopkins (see chapter 3 for more on the rhetoric offered by field professionals at this meeting).

At one time, Sheila's uncomplicated answer to my then-standard question about clinical relationships did not merit much further consideration. With the above information, this is no longer true, and for many reasons which I will discuss at length in the next two (concluding) chapters, I find Sheila's narrative of hand transplantation to be one of the most disturbing accounts of biomedicalization of physical disability in the hand transplant literature.

EH: *Do you feel like you have a good relationship with your doctors?*

SA: Yes, very good. …They're easy to talk to. They check up on me. They call or send text messages, just to check up, to follow up. I think that's wonderful, because not a lot of doctors are like that.

EH: *Yeah. Why do you feel like the relationship with your doctors is so strong?*

SA: I think, because they want the best for me, regardless of the hand. With the hand transplant they want to make sure that I'm doing okay, they want to make sure that I'm healthy… What my progresses are and what the changes are, so forth. I update them also, a lot.

EH: *Yeah.*

SA: Just the fact that everybody wants the best for it, with their hand transplant.

EH: *Do you feel like their interest is really about you?*

SA: Yes, definitely.

Narrative 7: Josh Maloney

"I remember them cutting my clothes off to check, make sure the rest of my body wasn't wounded and me trying to stay calm. As far as I know, I never went into shock. I never screamed,

I never cried, I never passed out," says former Marine and hand transplant patient Josh Maloney recalling the day he lost his dominant right hand. It was the second day of a two-day convoy training exercise and Josh was one of the leaders.

On that day they were using shot boxes, which Josh describes as "basically a big four-foot-long by six-inch thick steel tube filled with compressed air and baby powder, to simulate an IUD going off." Unfortunately, the box they were using was faulty, and instead of sending current on command, it was sending current all the time—so when one of the Marines skipped protocol and plugged the wires into the box without first checking that the charge box wasn't active, it detonated. Josh says that when the explosion went off, everything happened, "fast." "Diaz had his knees around my neck keeping my head straight. I had Marines with my arm out and I kept asking him, 'I know I'm messed up, but do I still have fingers? Is my arm gone? Somebody tell me something.' Nobody would tell me anything. I remember—it was January 31st, 2007, it was cold."

Josh kept his head throughout the life flight: "I laid there telling jokes trying to keep everybody else calm. One, I knew if I lost my cool, as cold as it was and as injured as I was, I would probably die if I allowed my heart to race, to go into shock or anything. Marines are a special breed. I knew my guys would take care of me, but anything they could use to make fun of me later, they would."

The oldest of four children, Josh says that throughout his life, he has had a strong sense of himself and his goals for life. Of his early and lifelong desire to be a Marine, he explains, "I always thought, watching war movies …I bought into—and I still do to some degree—that patriotic rhetoric. [As a career, it seemed] you get to play with cool stuff. I wanted to be a pilot, and then I realized how much math was involved and I was like, 'No, I'm good.'"

Once his family realized Josh was serious about joining the military after high school, since several family members had been sailors many of them assumed Josh would also join the Navy. Josh narrates, “I was already the black sheep for going in the Marine Corps. Then, [my family] wanted me to get a trade when all I wanted to do was blow things up. I was an 18-year-old kid. Think about the future or you're going to give me high explosives? I'll take the high explosives.”

I met Josh for coffee at a Starbucks near Moon, Pennsylvania, about 30 minutes from Pittsburgh, to conduct our interview on his experiences as the first recipient of a hand transplant at the University of Pittsburgh Medical Center (UPMC). By that time, Josh had undergone a self-requested amputation of the unilateral hand graft, having found the therapy and Rx protocols too burdensome to justify for his lifestyle long-term. Josh continued: “I take things as they come and don't really think about it beyond that. [I’m that] type of person. I don't care. In a lot of ways, I can take some subjects and think deeper on it, but things that happen in my everyday life, I don't.”

Patti Maloney, Josh’s mother and also a narrator for the oral history project, says that, “along with Josh not having strong opinions on anything, (as I say facetiously)—as he came into his own through being in the Marines and everything he became very strong-headed.”

Josh sincerely enjoyed and never regretted his career path into the Marines, despite being deployed twice to Iraq. Of that time, Josh recalls a comfortable relationship with duty and routine—“You didn't have to think. You didn't have to worry. You just did what was in front of you”—and amusing stories, “I remember being stopped on a security halt and an Iraqi vehicle went by that must have had dinner in the back, in the trunk, chicken. The chicken fell out because it was tied to a milk crate and it came undone. You have seven Marines fully armed chasing the chicken…”

I asked Josh whether he might be performing some optimism for the sake of the interview, at least in terms of his war memories. He answered, “No—I remember the bad things more often than the good. It was just—it was one of the scariest moments of my life. I turned nineteen in Tikrit on the air field that's outside Saddam's palace. It was scary as hell, but it was also some of the most fun I've ever had in my life.”

Patti says that despite reservations from the rest of the family, “Josh loved being in the Marines. After a couple years when he came back to visit, on one of those—I just looked at him and he wasn't that skinny little kid that went off, he was this big guy… I can literally remember the moment when I was standing there looking at him thinking, ‘Wow has he grown up and changed.’ Just that whole wow, he's no longer my little boy kind of thing.”

In the hospital after the accident, Josh says, he didn’t seem to fully appreciate the disabling nature of his injury, inquiring about his professional capacities rather than his health, “I came out of surgery, the first time after they made sure I was okay, and my platoon was still around me, they had all driven up to the hospital. I remember acting like, ‘When can I get back to work?’ Was the first words I said to anybody. I just wanted to go back to work. Then, I don't remember much after that.” Josh was transferred from the first hospital to Walter Reed, “where they did more surgeries and helped me heal up.” After mixed experiences at Walter Reed, Josh and his family negotiated his care back to Pittsburgh, where he was treated at UPMC and eventually, heard about hand transplantation. He says, “I started dating a girl whose aunt worked for UPMC at Mercy and that's how I heard about the transplant program. … She actually handed me a flyer than had been circulating through UPMC. We were at a family dinner and I actually called that number that night and left my information. I got a call back the next day.”

The evaluation process Josh describes as relatively straightforward, despite having little idea what to expect when the graft hands finally arrived. “They walked me through it all,” he remembers, “I had to get all the blood work and the psychological testing. To me it was all pretty easy because—being a Marine, to me, it was like, ‘Okay that's the next mission. This is what I want, this is what I want to do’ [even though] there was nobody that had done it before me that could walk me through the process and tell me what to expect. I knew going into it that I was the guinea pig.”

According to most hand transplant experts and Josh’s own clinicians, he had an excellent functional outcome in the early post-operative period of about two years. “Therapy was painful,” Josh says: “It was worth it but it was painful.” He quickly started seeing returns on his investment and recalls using the graft hand as an exciting experience. “I was getting really good with it. Really, really good. Way more than Vijay or anybody else thought I would ever get because I pushed myself. Then I started trying to... I got arrogant and stupid and thought that after a year of therapy, it was just going to stay that way that I didn't have to maintain it. I took advantage of it and I stopped paying attention and functionality went down.”

The more disappointing aspect of the hand transplant long term, says Josh, was the aggregate effect of all the work and worry that had to be managed on a day to day basis. The contingencies of life grew, yet his hope of returning to a combat role was not coming any closer to fruition. Josh says he grew weary of the constant surveillance and the experience of hand transplant patienthood. He also experienced episodes of acute rejection that were unpleasant and in some ways, off-putting to others. Patti Maloney remembers the long arc of Josh’s relationship with his graft as being affected negatively by complications of immunosuppression and the

transplant lifestyle: “[He was experiencing a lot of rejections and] I think it was in that time that Josh had just reached that point in his mind like he wanted to not have to be a slave to the routine.”

In retrospect, Josh thinks, “I did it for the wrong reasons. I did want to get back into the military, thinking that that would be my shot to get back in [to the military]. I kept thinking about that the whole time the process was going on for it.” Patti thinks that ultimately the hand transplant amounted to a role Josh played that he also grew out of in a timely fashion: “Josh was … the first one [at UPMC]. That's an awesome responsibility and I think he tried to live up to that for as long as he could and then he just didn't want to be that person anymore.”

Narrative 8: Joe Kinan and Carrie Pratt

Joe Kinan and Carrie Pratt are an impressively committed, seemingly truly cohesive, couple who met many years ago at an international conference for burn survivors. Carrie, a native of Ferndale Washington with an easygoing demeanor and sharp powers of observation, suffered a serious burn injury when she was just a baby and has been attending support groups for burn survivors most of her life. Joe, a victim of the infamous 2003 New Jersey Club Fire, is now the first hand transplant recipient at Massachusetts General Hospital’s emerging VCA program, and a soft-spoken person of amazing willpower.

Carrie’s description of her early life highlights her strong sense of independence and self-knowledge following a childhood in which bullying was an occasional feature. “I always wanted to be a nurse. But, uh, the four years in college was more than I could stomach. After not enjoying high school too much. I just had a different learning style and I was told in college it would be different but I just...wasn’t willing to give it a try—I wanted to start working right away, so, I passed on that and went to beauty school instead.” Joe who made his career in men’s clothing before the fire, like Carrie found work gratifying and a source of independence.

The couple met approximately ten years ago. Carrie describes that time period and the importance of the community that brought them together:

> "I was, um, in a bad marriage at the time, and my husband was also a burn survivor, and so the first year I came to World Burn was an extremely emotional experience for me. Just because of where my life was at home and just meeting all of these amazing people, strong amazing people, and Joe was, in the group with so many other new faces and he was just, um, happy go lucky and joking… When you look at him you would expect him to be um, like a little bit more… on guard or worried that he's gonna be judged. But that's one thing that I learned on that first day was that everybody there, if they're being there they're comfortable with themselves not necessarily outside of the conference but at the conference everybody comes out of their shell and they talk and joke and it kind of brings them back to who they used to be before their accident. I was introduced to him by the director of my foundation that I was there with, she had just run into him and she...brought us over and said, 'You have to meet this guy he's absolutely incredible,' and he just started cracking jokes about his appearance right off the bat and I just thought, 'This guy must have been through hell, and he's been through so much, and he—he still has this light about him and he's still so positive.' Uh, and we became friends after that conference. We didn't talk a whole lot but we would email a couple times during the year, and then we would see each other at the conferences during the year, and over the years of our friendship we would talk more often. Once I got divorced he kind of became my sounding board for everything I had been through and, you know because he wasn't a big talker he listened, which was really nice to have

somebody listen, and not judge you. So. And it wasn't until, we were in Galveston Texas, five it'll be five years ago this October uh, at a conference, that, something was just different between us. And I'd been divorced for, a year and, um, we decided that we would have a long distance relationship which was a little scary but, we made it work. Yeah, so we've been friends for nine, going on nine years I think."

At some point during the development of his friendship with Carrie, Joe's plastic surgeon in Boston introduced to him the idea of hand transplantation and invited him to consider being evaluated for their program. Because the extent of Joe's burn injuries caused the loss of all of his fingers, at that time Joe was able to do very little for himself: "I figured out how to get myself a glass of water. Just little things. I did eventually get a device, I made it myself actually with a friend of mine, that did work good in order to hold a fork so that I could feed myself. But getting dressed was an obstacle, shoes, pretty much everything. I did figure out how to hold my toothbrush…" After being offered the possibility of a hand transplant, Joe says, "I went home and thought about it and I called Carrie, who was just my friend at the time, and asked her what she thought about it. Then after her conversation I thought about it some more, 'Do I want to be on medicine for the rest of my life?', things of that nature." Carrie says that the idea of constant medications was especially hard to get used to, especially for Joe: "Joe's never been drunk in his life, he's never taken illegal drugs, he's never been high never smoked a cigarette, like he was—straight as an arrow, clean—when it came to bodybuilding the only supplements he ever took was protein powder…"

After the hand transplant, Joe and Carrie say they purposely remained in state of watchful awareness rather than emotional investment. Carrie describes that time:

> "We really didn't have any expectations which, I think, is a good thing. Um, I kind of compare it to, you know when you have a new baby you—are hoping that it's healthy, and that you don't have any health issues, and that your child's gonna be different than any other child. Whatever that is, um, but you can't expect your kid to be born, and to be a certain way that you have imagined in your head, and I guess that's kind of...what we did with his hand. He got this hand, and it was—a hope—that he would be able to do things that he couldn't do with the stump that he was left with. And none of it was immediate, at first the biggest milestone was being able to pick up a marble, um, and that was like two months in. And that was a huge deal."

According to both narrators, there was a long and surprisingly arduous period of adjustment before Joe got any real function and benefit out of the graft hand. Carrie says, "I would say the first three months were pure hell. It was...horrible. Um, and if that was something—that somebody could have told us before the transplant I think it would have made the transition a little easier? But nobody knew." Along with grueling therapy and nerve pain, Joe endured near-constant vomiting and nausea for over a year before his body adjusted to the medications.

One interesting and especially rare outcome of the hand transplant for Joe and Carrie is the rich familial relationship they have developed with the family who donated Joe's graft hand. Because Joe and Carrie's donor was a high school senior who died in a freak accident, it was easy for them to triangulate between demographic information they were given about the hand donor and the local news covering the tragic death. When Joe and Carrie first met the family, Joe says their connection was, "strange in a good way." He explains that it, "Seemed like friends that you hadn't seen for a bunch of years. We sat down and started talking. …I didn't know what to expect

and I wasn't trying to expect too much. Since then they have asked and we've accepted that [our newborn daughter] Hadley—if she could be considered their granddaughter—because her son's hand is on me so his DNA is inside of me now. They asked if she could be part of the family."

Although it may seem surprising to outsiders, phenomenologically *and* biologically Joe and Carrie say it makes sense for the donor family to participate in their life in this intimate way. Carrie describes their connection in strongly affective language:

> "We know in our minds that having this hand on his body had nothing to do with [our getting pregnant] because all the transplant medication Joe was taking should have, for all intents and purposes, made him sterile—even if he *hadn't* had a vasectomy. But it didn't. Um, so like, I've said, and Mary [the mother] says it too—it's like this little person is supposed to be here. We don't know for what reason, but um, it makes Mary feel better to think that Troy had something to do with it. It's not like, Joe took on Troy's DNA profile because he didn't. But, there's some part of Troy in Joe that's now Joe. The hand belongs to Joe, it's his hand, um—but I think it makes Mary feel better, thinking that there's some part of Troy… in Hadley. And when we told [our doctor] this he kind of laughed and he said hey, 'Anything's possible.' You know? Not that it's her biological grandchild by any means. But, um, that we don't know if we would have had her before. So, anything's possible, but she feels like this—this is her grandchild and we're perfectly fine with that. We love them to pieces, we absolutely love spending time with them, we were at their house last weekend, um—there was a big memorial softball tournament in Troy's memory and so Joe along with the family got to throw out the first pitch. Troy used to be the pitcher, at his high school, so... that was really

special for all of his friends to see, and all of his family, and, for his parents most of all, to see, um, Troy's hand doing what it used to do, which is, pitching, which ... was pretty cool."

Joe and Carrie are still navigating together the many challenges and opportunities of human hand transplantation. When asked what they would change or do differently if given the opportunity, Carrie says her only regret so far is the lack of adequate preparation and inability to accurately imagine the intensity of the early post-operative period, concluding, "I'm glad it took a whole year for us to get through the process. Um, being able to ask questions that we thought were pertinent to the surgery, the one thing that we did hold back on was—and Joe expressed this to me later—was, 'I'm afraid to ask too many questions because I'm afraid they're gonna say, we changed our minds, you're not a good candidate for this.'" Carrie emphasizes the extent of this mistake anecdotally: "[Our doctor] Curt said, 'That's the stupidest thing ever, you could ask us anything and there was nothing that was gonna change our mind about you being the first patient at MGH to do this.' Um, so it's—I think that would be one of the things I would tell patients is, 'Don't' be afraid to ask every question that's on your mind.'"

3.3 ORAL HISTORY OF HAND TRANSPLANTATION: THEMES AND CONCEPTS

Based on the interviews with hand transplant patients and their caregivers, I present several thematically organized "gestalt" insights pertinent to understanding what counts for success in this field, and how success has been achieved through the mental and physical work of patients and those who support them. Taken together, the narratives illustrate that in hand transplantation, compliance is a collective achievement of medical providers, caregivers, and patients rather than

the sole burden of the hand graft recipient. Second, physical sensation, manual and psychosocial function, and the health of a hand transplant are deeply related categories of the HTX experience and should be treated as such in scientific measurements of efficacy in hand transplantation. Finally, insofar as "success" is achieved in HTX, it can only be defined by the conceived desirable outcomes of the hand transplant as envisioned by the patient and their family.

"Compliance" is a collective achievement

Researchers in the field of hand transplantation make much of the process of patient selection and the need for strict adherence to immunological protocols and hand therapy guidelines. When guidelines are not followed, patients can be charged with "noncompliance," which effectively brands clinical interventions as *personal* failings if the treatment ends badly (see chapter 1 for discussion on noncompliance issues in the first modern case of human hand transplantation). There has, however, been little work to understand longitudinal compliance and its challenges from the viewpoint of patients and their caregivers who carry out the work from day to day (Kumnig and Jowsey-Gregoire, 2016).

In addition to engaging in hand therapy and medication management for the rest of their lives or the lifespan of the graft, patients and their caregivers must perform the real work of forging and maintaining the relationships that make hand transplants possible. From the start, hand transplants involve a host of actors and actants—a huge network of laborers are needed not only to organize and perform the transplant medically, but also to help the patient care for the hand graft, to guard against outside threats, to interpret signs (e.g., of infection or progress), and to help shape new meanings in response to contingencies. As Angel Gonzales describes in his oral history interview:

> "[My partner's arms]...were basically dead weights, in these casts, and swollen and just, needed constant maintenance—you know, we had to unwrap the arms, wrap the arms, uh, multiple times a day, massage them, work them out it was just a regime of things that, basically by the end of the day you were glad that the day was over!"

Because in the short term of hand transplantation, functionality will go down before it goes up, for bilateral HTX patients especially family caregivers or attendants have to be willing to put in as much work as the patient. These care activities may or may not be aspects of the recovery process that they relish or even expect.

In hand transplantation, for almost all aspects of the preparation, surgery, and aftercare, as the saying goes, "it takes a village." In their seminal 1977 book on architectural evolution and livability, *A Pattern Language: Towns, Buildings, Construction*, authors Christopher Alexander, Sara Ishikawa and Murray Silverstein write, "when you build a thing you cannot merely build that thing in isolation, but must also repair the world around it, and within it, so that the larger world at that one place becomes more coherent, and more whole; and the thing which you make takes its place in the web of nature, as you make it" (p. xiii). Recalling the surprisingly wide and robust circle of effect the hand transplant had on his social relations, Matt Scott said, "'I started to realize that this is not just me. This is everybody around me. Everybody around me who knows me, even my friends will go, 'Hey, you're friends with that guy who got the hand, right?'… It spread that far out that it affected more than just me and my small nucleus. It went far around me.'" Matt Scott's experience was unique due to the way his experience of celebrity patienthood contributed to the social effects he describes—nevertheless, hand graft recipients across my oral history interviews have remarked on the local, rather than individual, effects of these types of transplants.

Whether clinical, familial, or collegial, the relationships supporting the substantial work of hand transplantation are crucial to patients' thriving. Instances during which the shared nature of "compliance" in hand transplantation can be especially visible are those in which HTX recipients were considering exit strategies. Josh Maloney recalls, "I was afraid to disappoint [my doctors] when I told them that I wanted to have the hand removed. When the functionality started dropping, I felt like I was disappointing them. I felt bad because of it. … I finally just said, 'I think now is the time. I've given it everything I can, it's not getting any better.'" Even in the less intensive rehabilitation processes of solid organ transplantation, care providers typically consider it part of their job to check in on their patients, to motivate them in completing care protocols, and to communicate consistently about health events. As organ transplant clinicians Williams, Low, Manias, and Crawford argue, "A quality partnership with frequent interaction between the health professional and patient is necessary to support medication adherence… Post-transplantation, patients require repetition, reassurance and re-enforcement long-term by staff trained in adherence counselling within a supportive healthcare system as taking multiple doses of different medication every day is taxing" (2016, p2252 and p2260).

Jan Plock, a plastic surgeon and burn care physician in Zurich who is starting a VCA program in Switzerland, was a resident at UPMC, Pittsburgh, when hand transplants were being performed and treated there. In a Skype interview Plock says he observed loose obligations to patients among some HTX doctors (compared to the personal commitments held by counterparts in solid organ transplantation) and the high cost for patients when their care team was unreliable or constantly changing:

> "What I see in other transplant centers is that the centers really have a very strong connection to their patients, and I think there are huge differences in the different

> U.S. centers. For example, the [Brigham and Women's Hospital] team seems to have a very strong communication with their patients; other teams who did a very low number or a few patients have this quality. Then there are other teams where there is only *one* surgeon who has this quality of relationship with the patient so the *team* can't handle that relationship, it is more of a personal commitment … Observing the situation at UPMC the only thing I can really say is the patients were not happy with the situation, and the situation is that their doctors, the surgeons who had transplanted them, were not there any more. The hospital was the providing institution so they were bound to this hospital and the doctors that were there were not the ones that had initiated the process. And this is a really neutral statement because nobody could do anything about it [at UPMC]. They didn't know or had not known before [that the program was moving to Johns Hopkins]—the situation just changed."

Because many hand transplant recipients live a long distance from their center of care (especially in the U.S.) maintaining therapeutic relationships can be particularly challenging. Many narrators expressed dismay recalling how many trips they had to take for yearly checkups and to manage complications—trips which were made at their own expense, a fact which caused bitter feelings in some cases. Other recipients have found the necessary migrations of hand transplantation to be enjoyable on some level, "I have since come to think of Louisville as a home away from home," said Matt Scott describing his regular visits there. For HTX patients who experienced the phenomenon of their original clinicians leaving for new opportunities or to start VCA programs in other places, advocating for their own interests with newer doctors who did not

know them from the beginning of their treatment was uncomfortable and problematic (see narrative 4, Dave and Karen Savage for quotes on this effect).

Function, sensation, and sensitization: Irreducible issues

In conversations with friends, family, or colleagues about my research on the history and ethics of hand transplants, Luke Skywalker's robotic hand is a cultural touchstone of frequent reference. When discussing tradeoffs between hand transplants and prosthetic technologies, I sometimes mention Luke's sophisticated bionic hand as a foil: we're not there yet. Often, the catwalk on the cloud planet is recalled because most of us have trouble *conceiving* of the loss of a hand—and Luke is a rare protagonist who dramatically and visibly suffers this fate in a major motion picture. As an aid to imagination of the amputation or transplantation of human hands, I find STAR WARS imagery intriguing because Luke's loss is so theatrical yet so *quickly* made a non-issue through advanced biotechnology. Luke's device is dexterous, strong, touch-sensitive, and always functioning. Following the scene in which Luke is fitted with the prosthetic, audiences are able to forget the loss ever occurred and thereafter must be reminded through staged gestures and meaningfully panned shots that the movies' hero is in fact an amputee.

The functional, aesthetic, and overall therapeutic differences between transplant hands and prosthetics are a key source of interest and speculation for hand transplant doctors, candidates, and recipients—as well as ethicists, payers and policy makers who work to determine the best care options for their communities within the limits of available resources. As pointed out by hand transplant providers, prosthetics are often rejected by their users for reasons that include their awkward social nature, their heavy weight, and the fact that they must be taken off frequently (Kay and Wilks, 2013). Matt Scott describes his bionic hand: "It had its limitations. It was battery-powered, so that was always something of concern is that I always had to have a spare battery or

two with me, making sure that if the battery power started to wane, I had something to quick pop in and pop out. It was uncomfortable and it was unbalanced. It was heavy, particularly on the distal end, where the hand is, because that's where all the robotics were."

While the spectrum of function for hand transplants is broader than for prosthetics (including return of touch sensation, warmth, and "human"-ness) hand transplants do not necessarily work better than prosthetics to improve their users' quality of life. A hand transplant unlike a prosthetic is a constant presence on the body both affording and constraining that person's action and movement through the world. Narrators for my oral history project almost unanimously experienced functional gains with a hand transplant that were impossible with the prosthetics they had tried, yet these gains were made *within the parameters of the post-transplant lifestyle*, including restrictions on diet, lifestyle, budget and freedom to travel in the short or long term. While hand transplants and bionic prosthetics both require extensive learning and rehabilitation periods before they are useful for even the most basic tasks, many who pursue hand transplantation after using bionics emphasize that the work needed to maintain a hand graft and the demands of post-care protocols were far more intense than any physical therapy they had previously experienced.

Because hand transplants can bring dramatic functional returns but are also biological gifts from another person, gains can be set back by immunological complications. "Sensitization describes the acquired ability of the immune system to react to [foreign tissue] by producing antibodies and developing memory cells," write VCA biologists Klein et al in a paper on the science of rejection in reconstructive transplantation (2015, p. 247). During a rejection episode, a hand transplant can swell and grow painful, develop spots or lesions, itch, and burn. Of course, the social and manual function of hand grafts go down during rejections, as the graft(s) might be too

swollen or hurting to use, and the aesthetic presentation of rejection can be off-putting to others (as one family caregiver described, “You come to the point that [you want to ask] ‘Is your, is that hand *dying*?’ It's not right, let's put it that way. It's not getting the right blood flow—or, is it in rejection?”

Following a rejection episode, a transplant patient’s immune system is likely to be more sensitized to their graft, and any fluctuation in medications could result in further rejections (especially alterations made intentionally to deal with systemic bacterial or viral infections where turning down immunosuppression is necessary for recovery) (Krezdorn and Pomahac, 2017). Even long after rejection episodes, effects can be felt in the subtle loss of dexterity and sensation that can occur with them (possibly because of swelling or attendant vasculopathy [hardening blood vessels]). “I would say the first couple years were the best results he had,” recalls Karen Savage at the end of our oral history interview. “Dave was using his hand for everything. Then each time that he's gone through one of these episodes where there's swelling and pain, he comes out of the episode, but with less function on his hand.” Josh Maloney recalls similar struggles:

> “I was getting really good with [using my graft hand]. Really, really good. Way more than Vijay [Gorantla] or anybody else thought I would ever get because I pushed myself. Then I started trying to ... Okay, I'm going to go back to school and I'm going to get a job, [so] I got arrogant and stupid and thought that after a year of therapy, it was just going to stay that way that I didn't have to maintain it. I took advantage of it and I stopped paying attention and functionality went down. Then, I was outside more and I was going to [technical school] working on cars for school and started having more rejection issues, and more and more rejection issues. The meds kept getting stepped … Eventually, it just got too much.”

When Josh and his family has seen “the writing on the wall” as he says and he exited the program with a second hand amputation, Josh nevertheless felt that the hand transplant experience “taught me what I can make myself do and what I'm capable, mentally. I always say it, but I don't think I quite believed it until during and after the transplant that disability is a state of mind. I'm wearing my prosthetic now, but I can still do most everything that everybody else can do with two hands. I've just learned to adapt.”

For others, even if the donated nature of hand grafts can cause fluctuations in health or frustration in terms of the transplant lifestyle, hand transplantation is an operation that can return life-giving function unparalleled by other reconstructive options. Sheila Advento explains the real joy she feels in having her graft hands: “just the fact that I'm able to do so much more. It's exciting for me. For instance, I'm able to grab somebody's arm, I'm able to hold somebody's hand, I'm able to hold my boyfriend’s hand. It's a nice feeling. Not having hands, eventually you lose the intimate feeling.”

“Success” begins at conception

Imagining what a hand transplant will be like, and what it will represent in terms of a change to the life course of a person and their family—including aspects of lifestyle, value, and identity—is a process requiring several intertwining avenues of deep concern. Patients and caregivers must work to discern whether a hand transplant will be affordable for their family and whether the biological risks (including lifelong reliance on and weakness from toxic immunosuppressive drugs, surgical complications, and possible graft-related illness) will be worth the psychosocial benefits that may or may not follow as a result of the hand transplant. For bilateral amputees, the calculus is especially precarious: if the transplant fails, they could lose valuable time

learning how to use their prosthetics, or they could be set back in their ability to wear prosthetics for months or years due to an additional healing period before getting fitted for a second pair.

Having time to imagine all the possible outcomes of hand transplantation and associated challenges was an important factor in long term success according to several narrators. As Carrie Pratt notes above, "I'm glad it took a whole year for us to get through the process. Um, being able to ask questions that we thought were pertinent to the surgery..." Still, Carrie along with many other narrators in the oral history project expressed a sense of frustration regarding the gap between how difficult they imagined the HTX recovery process being and how difficult it actually was (hard to the point of unmanageable). Matt Scott says the daily labor of the transplant and the necessity of being away from home for several months post-transplant for therapy and observation was the hardest part, "I knew that there's going to be work, but I didn't realize how much work it was going to be. I don't think that I had an understanding—and I've reported this back to the team as well—the people who are coming in, they have to understand what they're getting into. Beyond medication and beyond the therapy it's just it's going to be hard, hard work, and I don't think I was ready for that. Psychologically, I wasn't ready for it." Many narrators recall with pride or a sense of self-satisfaction the hard work they put into the hand therapy and how this work showed through in their evolving ability to manipulate the world around them. Vasyly Rohovyy narrates, "It took a lot of time, as I said, three years. I did the therapy for three years. I know, there is very few patients who did therapy for so long as me. I learned a lot of things that I took for granted before the explosion. To eat. I had to relearn everything, to dress myself, to eat with fork, spoon, to open a bottle."

In the above narratives, patients described hand transplant successes and their level of satisfaction in relation to what they had conceived, prior to transplantation, as likely desirable

outcomes. For example, Josh Maloney describes having hoped to regain a combat role in the military after hand transplantation and, failing this outcome, he stopped going to hand therapy every day; requested re-amputation of the graft quickly followed. Josh reflects, "Truthfully, I did it for the wrong reasons. I did it to get back into the military, thinking that that would be my shot to get back in. I kept thinking about that the whole time the process was going on for it." A similarly powerful yet erroneous conjecture about what kind of life would be possible with new hands led to dissatisfaction and disaffiliation in the case of Rich Edwards. For a short period, hope itself seems to have been a *telos* of Rich's hand transplant treatment, an end in itself conferring reinvigorated purpose to his shared life with Cindy, from which new meanings could have—but unfortunately did not—arise. Because their hand grafts were unable to take on new meanings after years of grueling therapy did not afford the hoped-for outcome, the semiotic calcification of these HTX as "unsuccessful" in specific endeavors led graft loss for Josh and even more severe consequences for Rich (depression and suicide).

Software engineers are familiar with the problem of overdetermination of methods and endpoints in designing and implementing new technologies. The following passage from a paper describing parallels between engineering and evolutionary biology sketches concepts that are relevant to the unfolding contingent, iterative, and enmeshed technologies of hand transplantation:

> [W]hile human engineers are certainly goal oriented in the short run and nature is not, their guesses as to what a new device might eventually be used for often fall flat … adherence to a strict linear approach to design has often been identified as the key reason for the frequent failure of large-scale software projects, which some estimates put at over 50 % of projects. It is common, for example, for precise requirements to be unclear at the beginning of a project, and many complex design

> problems often don't come into view prior to implementation (Calcott, Levy, Siegal, Soyer, and Wagner, 2015, p. 54-55).

This description of an "iterative" design process in highly interactive technological disciplines is similar to challenges associated with demanding, constantly unfolding, medical interventions like hand transplantation.

One recurring theme in my oral history interviews that I found fascinating and instructive—voiced on separate occasions by patient families who did not know one another—was the metaphorical comparison to their experiences as caretakers of hand grafts to the processes of attending, working through, and cautiously observing the development of a baby or child. Angel Gonzales gave the analogy in buoyant, but also serious, terms:

> "I didn't see [the work of HTX rehab] as frustrating, because I mean, this kind of thing is exciting—to me it was, I guess the closest I'll ever be to ...having a child? Haha, so it was kind of like, I dunno these sort of instinctual things come with it. … I think when Will has fully regained sensation—or *if* he fully regains sensation, uh, and proprioception, so that he doesn't have to think about where his arms are—um that will be the sort of... the day that like, the baby's grown up! [Laughing]"

Carrie Pratt offered the "baby metaphor" to illustrate what it's like to both hope for an outcome while also holding that hope in tension with the knowledge that it could be otherwise, "I kind of compare it to, you know when you have a new baby you—are hoping that it's healthy, and that you don't have any health issues, and that your child's gonna be different than any other child. Whatever that is, um but you can't expect your kid to be born, and to be a certain way that you have imagined in your head."

Conclusion

Building on the traditions and insights of oral history, grounded theory, and narrative medicine, this chapter provided eight oral histories with hand transplant recipients and their partners or family caregivers. The interviews illustrate the unending nature of the hard work of hand transplantation, but also the unique joys and capacities for life and self-transformation that HTX can provide well-prepared and cared for patients. In the last section of this chapter, I highlighted three themes that run across these oral histories: first, that compliance is a collective achievement of medical providers, caregivers, and patients. Second, that physical sensation, manual and psychosocial function, and the health of a hand transplant are deeply related categories of the HTX experience and should be treated as such in scientific measurements of efficacy in hand transplantation. Finally, that "success" is determined by the conceived desirable outcomes of the hand transplant as envisioned by the patient and their family.

Regardless of how hand transplant patients might envision an intervention like hand transplantation in terms of restoring their quality of life or a specific function, outcomes in this field will always be a complicated palimpsest of pre-existing associations and novel, as-yet-uncategorized sensations. For this reason, anticipating that a hand transplant will allow for the return of a former lifestyle or career may be impractical or a dangerous recipe for disappointment. When assessing quality of life outcomes in hand transplantation, patient-centered must mean patient-defined—even if the imperfect, intuitive definitions given by patients means working with a vocabulary that is possibly resistant to standardization. I argue in closing this "keystone" chapter of my dissertation that the goals of a hand transplant are emergent, not predetermined: patients do not reach a discreet destination or point of full recovery but will rather see gains and losses in psychosocial and manual function over time due to complications from drugs, rejection episodes,

or the limitations of the post-transplant lifestyle. In the next chapter I discuss the scientific, ethical, and human costs of failing to recognize the unfolding contingent nature of success in hand transplantation.

4.0 THE RHETORIC OF "SUCCESS" IN HAND TRANSPLANTATION

"'To the pain' means the first thing you lose will be your feet below the ankles, then your hands below the wrist, next your nose and then your tongue. The next thing you lose will be your left eye followed by your right. *Your ears you keep, and I'll tell you why:* So that every shriek of every child at seeing your hideousness will be yours to cherish. Every babe who weeps at your approach, every woman who cries out, 'Dear God, what is that thing?!' will echo in your perfect ears. That is what 'to the pain' means: it means I leave you in anguish, wallowing in freakish misery, forever."

~ Westley, *The Princess Bride*

"We know that Mary Shelley's hero, Frankenstein, [sic] was made of pieces of human bodies sewn together. The first time a patient sees his newly grafted hand, the sight is rather awful. Stitches, threads, the swelling of the hands and the additions, the possible different colours of the skin … The unnamable is there. The perception is traumatic and revives the idea of the lifeless coming back to life."

~ G. Burloux, "Hand Transplant and Body Image"

in Lanzetta and Dubernard, 2007, p. 378

After over twenty years of human research and clinical trials, there are no commonly accepted rules or conventions characterizing how and when "success" is attained through hand transplantation (HTX). In the early years of the field, outcomes of single case studies were published promptly and with preening self-congratulation by clinical professionals directly in charge of or involved with the events (see chapter 1). The outcomes reports on the first hand transplants in Louisville and Lyon confirm the "success" of these procedures in terms of a technical

(early surgical and immunological) result and many of these reports were immediately and uncritically cited by peers as showing proof of concept for further hand transplants and for the diversification of hand transplants to other conditions (collectively called "VCA"). Regrettably few of the scientific and ethical debates on hand transplants' effectiveness feature discussion on whether the interventions successfully returned the "quality of life" (QoL) gains that figured so prominently in preclinical ethical debates.

In the preceding chapter of my dissertation I argue that the under-appreciated and often, uncirculated narratives of hand transplantation from patients' point of view can offer visceral complications to decontextualized representations of results given in scientific review articles and case reports. In the first section of this chapter I show how "successful" outcomes in hand transplantation are produced by stakeholders through a series of rhetorical gestures in which empirical findings from preselected scientific and psychosocial assessment tools take the place of "commonsense" conclusions and firsthand observations of patient participants. As I will show in my descriptive analysis of these medical texts, having read and imaginatively entered (Yow, 2015) the vicariously rich imagery and personal language of the oral history narratives, gestalt traces of these account will—I hope—settle like a lens upon the mind's eye when re-encountering clinical voices in chapter 3, helping to bring certain features of medical storytelling into relief. These sense impressions from patient narratives of hand transplantation, far from being "merely" descriptive or emotional edgings to scientific accounts are, I argue, pertinent tools for interpreting the given information in many academic-professional contexts—which might otherwise be "sanitized" from their resonances—since patients' own subjective experience of their QoL is both the occasioning *and* the ongoing clinical and ethical justification for hand transplants.

In part two of chapter 3 I think through the concepts of medicalization, biomedicalization, and the social model of disability to unpack how such dehumanizing rhetorical conventions have come to characterize outcomes reporting in this field of human subjects research. To do this work, I bring voices from bioethics, disability studies, and science and technology studies (STS) together with my own data and observations to argue that "success" is a misnomer in complex biomedical interventions like hand transplantation and claims to success a problematic distraction from patients' lived reality which involves complicated tradeoffs of health for quality of life that are never fully resolved. There is a recognized need for more robust integration of STS concepts regarding largescale developments in medical science and practice, with insights from disability studies on how those developments affect populations "on the ground." In a call for papers for the 2019 meeting of the international Society for Social Studies of Science (4S), organizers write that such integration is needed and timely:

> In STS, for all the considerations of the posthuman, critical conceptualizations of disability remain rare. The research, then, emerging from these fields has largely run in parallel, with few or fleeting intersections. If the conceptual and political points of reference in these fields are characterized largely by disjunctions, the same cannot be said for their subjects of interest. From studies of biomedical technologies such as pharmaceutical and bionic devices to studies of the senses and ways of being in the world, the subjects and objects of concern in critical disability studies and STS overlap significantly (https://www.4s2019.org/accepted-open-panels/ "Beyond the Prosthetic Imaginary: New Intersections between STS and Disability Studies).

Because hand transplantation makes transformations to bodies from the inside out requiring the enmeshed participation of several biotechnological disciplines and processes, this approach of wholesale transformation (changes sustained at the cellular level), rather than localized restoration represents, I argue, the "biomedicalization" of human hand loss. Consequently, the increased degree of surveillance and self-transformation attending HTX must be taken on board in evaluations of effectiveness. I conclude this chapter and the argument of my dissertation by explaining why, when efforts to transform the human body are rebuffed by organic complexity (in the form of rejections, infections, and other biological complications) iterative evaluative work is needed to illuminate tradeoffs for patients in the long term.

4.1 "SUCCESS" IN HUMAN HAND TRANSPLANTATION: CONTEMPORARY PERSPECTIVES

Hand transplants were the groundbreaking surgeries in VCA, and accordingly many of the ethical and technical arguments justifying hand transplants to peer researchers and the public can be considered, themselves, *successful* in eliciting support for what is now an international field of chronic care medicine. The first hand transplants in Lyon and Louisville were figured as surgical successes in media reports as early as days after the operations (see chapter 1). Following only six months after transplanting Clint Hallam (who notoriously requested amputation of the graft two years later) the Lyon team writes, "We have confirmed the technical feasibility of limb transplantation" (Dubernard et al, 1999, p. 1318). After just one year, the Louisville group published similar conclusions, "Our results and those of the first human hand transplantation,

performed in France, show that early success in hand transplantation can be achieved with the use of currently available immunosuppressive drugs" (Jones et al, 2000, p. 472).

After over twenty years of human trials, success claims in the field of hand transplantation are no more sophisticated in terms of their empirical significance than they were in the early, fevered years of human experimentation and "proof of concept" studies. Because straightforward, dispassionate representations of illness events are a stylistic convention in medical reporting, one is obliged to read *beyond* the lines—imagining the human experiences on the ground being represented by the abstract statements—to appreciate why some articles' recitation of relevant sequelae feels wrongly unreflective or inauthentic in terms of proving the effectiveness of hand transplant interventions.

Consider the following study from a hand transplant research program at Duke, University in Durham, North Carolina, which argues for the efficacy of a novel immunosuppressant drug in caring for HTX patients preceded by an unelaborated yet seemingly well-populated list of complications from the hand transplant aftercare and experimental immunosuppressive regimen:

> At [post operative month] 4 the patient experienced an increase in serum creatinine of 1.3 mg/dL and a tremor that resolved with a reduction in the tacrolimus dose. At [post operative month] 6 the patient reported increasing fatigue and fever. The results from routine screening for viruses were within normal limits. He was admitted to the hospital and medication- induced neutropenia was diagnosed… During his 8-month belatacept infusion visit the patient presented with round erythematous, nonblanching macules …. At 1 year the patient reported mouth ulcers and new, asymptomatic skin lesions localized to the allograft (Cendales et al, 2018, p. 1805).

Despite these reported complications in the short term, in the conclusion of their paper, Cendales et al write that, "We have shown that hand transplantation can be performed using a de novo belatacept- based treatment in a CNI- free regimen, providing sufficient prophylaxis from rejection, reversible rejection when occurred, and reduced side effects, the latter particularly important" (2018, p. 1806). Revealingly, the authors do not mention the fact that their patient resides extremely far away from the transplant center but was personally responsible for getting to and from his monthly appointments. Cendales et al write: "Per protocol *the patient resided locally for 3 months* and returned to his local residence in month 4. Thereafter, *the patient returned to our center monthly for his belatacept infusion until the end of the study period at postoperative month (POM) 18*" (p. 1805, italics added). These are significant details because in traveling to these mandatory monthly appointments, the patient—who lives in Laredo, TX, on the border with Mexico—had to travel a distance of over 1,400 miles to Durham, North Carolina for these experimental treatments. One might commonsensically wonder what other tradeoffs have been experienced by this patient in terms of the hand transplant when we have no firsthand feedback from him on the gains and burdens he has experienced in any publication or presentation by Cendales's group so far.

Regrettably, the example related above is not an isolated case of abstract representation of patient experience at the service of "progress" in the hand transplant field. At every conference I have attended on VCA (three so far), the need for consistent outcomes reporting has been emphasized by field leaders but no strategies have been agreed upon for filling empirical gaps. There is an International Registry of patient data but it is not complete or up to date lacking insights from many programs and patients. Furthermore, patients who have lost their hand grafts are not followed at all, and complications, including patient deaths, are not discussed in the media with as

much regularity as successful surgeries or milestones. Even when outcomes are published in a timely fashion and a patient followed over time, manual function (grip strength, etc.) and the clinical management of immunosuppression or rejection/infection are discussed, but not the factors contributing to patients' quality of life post-transplant. Thus, the impact of managed complications and the post-transplant lifestyle (including travel to and time spent in the hospital and at appointments, or the temporary loss of manual and social function during recovery from surgery and from infections/complications) are not considered—after 20 years of hand transplantation we can find out almost nothing about patients' lives from the literature and even conferences are thin on this aspect.

As Judy Segal writes in *Health and the Rhetoric of Medicine*, "The most salient narrative of medical history is the narrative of progress, the narrative that says, 'We used to have things wrong, and now we have them right, or are on the road to having them right'" (2008, p. 21). When clinical researchers push success narratives, publishing and discussing primarily quantitative "scientific" variables from their experiments without considering complicating on-the-ground participant perspectives, a dangerous loss of focus on research subjects' *personal* interests in the outcome of experimental interventions can occur. This is emblematic not just of one-off case study representations of success in hand transplantation but also of the "top-down" rhetoric from contemporary field leaders. In a recent feature-length article on hand transplant outcomes by science journalist David Dobbs, the tendency of hand transplant thought leaders to present outcomes in terms of their own needs and not their patients' is strongly highlighted. Dobbs interviewed me for his article on modern hand transplant outcomes and I encouraged him to attend a scientific meeting on the topic. Dobbs acquired a media pass for the 2018 conference of the

American Society for Reconstructive Transplantation (ASRT), giving the following reflection on representations of patients' experiences by surgeon-scientists at the meeting:

> [S]uccess was the theme of the conference that day, and [Gerald] Brandacher [head of the ASRT] underscored that idea in his opening speech. Just as solid-organ transplants had moved 30 years earlier from doubt to acceptance, he said, so reconstructive transplants were poised to do the same. Challenges remained. Now that many patients had been on immunosuppression for years, Brandacher noted, they were suffering more renal complications and chronic rejection of the grafts. In his opening talk at the conference, Brandacher acknowledged that the VCA field had not resolved all its issues. But his main message was one of success and the need to move forward. Most of the day's talks followed this lead. The last speaker of that afternoon's long opening session, a bioethicist, in fact, ended by crying, "Let us plow forward with this incredible field!" (https://www.wired.com/story/devastating-allure-of-medical-miracles/)

As demonstrated above and in previous chapters, when doctor-scientists create opportunities for their patients and also *frame how those opportunities will be managed and assessed*, professional considerations in the literature may travel farther and farther from the site of the patients' and their families' ever-evolving needs in relation to their own health and even the health of the hand graft(s). As Stefan Timmermans and Marc Berg warn in their 2003 book on evidence-based medicine, *The Gold Standard*, "the emphasis on following standard procedures, based on scientific evidence, could leave precious little room for patients to influence the course of their own care trajectories. Moreover, an emphasis on objective evidence might direct the physician's attention even more to laboratory tests and other objective measures of the patient's

condition, and belittle even more the importance of the patient's own story and experiences" (p. 118). If, as Timmermans and Berg argue, representing patients' experiences in such unrealistically calculated ways is contrary to medical knowledge and possibly ethics, *why* have reductive quantitative methods for assessing medical outcomes become the seemingly "natural" vocabulary for doctors relating case studies to their peers (especially in a field like hand transplantation where the stated goal of the treatment is subjective improvement to patients' quality of life)?

To illustrate how such ungrounded, seemingly out-of-touch vocabularies have come to dominate clinical discussions of outcomes in this and other fields of medical science, the next sections explore the concepts of medicalization and biomedicalization as they relate to the evolution of treatments for hand loss in the 20th and 21st centuries, turning first to disability scholars for a critical framing of key developments and processes.

4.2 HAND LOSS, PHYSICAL DIFFERENCE, AND THE "SOCIAL MODEL" OF DISABILITY

In the above epigraph, a French psychoanalyst and participant in several of the world's first hand transplants, Gabriel Burloux, invokes images of Frankenstein's monster to emphasize fears of psychological rejection in early hand transplantation (in Lanzetta and Dubernard, 2007, p. 375). Notable in Burloux's chapter, the ontological state of being "pieced and sewn together" is the speculative source of horror—a somatic fact eliciting revulsion from others or from oneself. Since I started writing this dissertation project, images of Frankenstein's monster have entered my mental and visual field of view with increasing regularity as 2018 marked 200 years since Mary Shelley first liberated her "hideous progeny."

For me, Shelley's haunting depiction of scientific tragedy is made more unsettling because the story's horrific ends emerge not from defects in the monster-protagonist's nature or character but as an outcome of the unearned abuse and "othering" the creature endures from *every* person to whom he appeals for the most basic of human needs: care. Here is the creature approximately mid-way through the novel, begging his creator for a chance at life, which he characterizes as life with seemingly any amount of affection in it:

> "I learned from your papers that you were my father, my creator; and to whom could I apply with more fitness than to him who had given me life?" … he continued, "If *any being* felt emotions of benevolence towards me, I should return them a hundred and a hundredfold; for that one creature's sake, I would make peace with the whole kind! But I now indulge in dreams of bliss that cannot be realised. What I ask of you is reasonable and moderate; I demand a creature of another sex, but *as hideous as myself.* The gratification is small, but it is all that I can receive, and it shall content me. It is true we shall be monsters, cut off from all the world; but on that account we shall be more attached to one another. Our lives will not be happy, but they will be harmless, and free from the misery I now feel. Oh! my creator, make me happy; let me feel gratitude towards you for one benefit! Let me see that I excite the sympathy of some existing thing; do not deny me my request!" (Shelley, 1994, p. 99-100 & 105, quoted from Dover Thrift Editions, republication of the third edition of *Frankenstein* (chapters 16 & 17); italics added).

This pitiful appeal follows several chapters of acute emotional suffering by the creature in which his gestures of friendship and bids for inclusion in human society are met with fear, revulsion, and physical violence by individuals and whole communities. The creature has learned to care for

himself but longs to be cared for, in turn—the same way he has observed (from afar) human families caring for each other throughout his solitary travels.

Much has been made by literary scholars of the negligence of Doctor Frankenstein in his abandonment of his living creation. As an archetype, or foil for, differing concepts of scientific progress, an overlooked feature of Mary Shelley's groundbreaking novel are the less dramatic, yet richly narrated character-building events in which the unnamed creature's tremendous capacity for human connection are demonstrated through his eloquent words and compassionate behaviors. What clearly prevents this individual's personhood from evolving fully, in Shelley's depiction, is his lack of an acceptable degree of human appearance or an advocate of "normate" status (Garland-Thomson, 1997, p. 8) who could translate his physicality as not-monstrous, but different. As science and technology scholars Megan Halpern and colleagues write in an article that reinterprets *Frankenstein* for interdisciplinary readers, the Victorian horror story that pervades so much of contemporary bioethics and technoscience discourse is about, "what it means to care for, or fail to care for, one's creation," as much as it is "a cautionary tale about the evils of scientific hubris." Halpern et al conclude of their study that, "[Shelley's novel is] a parable about the dire consequences of care's absence … [and it] … cautions us against abandoning our creations to the world; in order to protect both the creation and the world, we have to take part in the discourse and deliberation about how it is taken up and integrated into its social contexts" (Halpern, Sadowski, Esrich, Finn, and Guston, 2016, p. 49-50 & 55).

Burn survivors, people with congenital deformities, and others whose physical appearance has been a source of exclusion or abuse by society often gain critical resources for life through the advocacy of a friend or family member or through laws that have been advocated which protect their rights to equal treatment (Davis, 1995; Schweik, 2009; Johnson, 2010, p. 474; Kafer, 2013,

p. 30; Dolmage, 2017). Victor Frankenstein could have served as such an advocate for his abused creation—much the same way Dr. Treves defends difference in the acclaimed film, *The Elephant Man*—but for no reason given other than the creature's "monstrous" physicality, he does not.

Frankenstein's sentient creature is in considerable company as a fictional sufferer of human intolerance for physical difference. In the majority of narratives where disability and disfigurement are pictured, the storylines of disabled characters—typically not main characters—follow a predictable course in which restoration of form or function is a goal for which the afflicted strive (often aided in their pursuit by wealthier, healthier "normate" characters). In her 1997 book, *Extraordinary Bodies*, disability scholar and professor of English and bioethics Rosemarie Garland-Thomson laments the limited range of depictions of disability in modern culture. The representations that largely make up our (western) perceptions of disability and physiological difference, Garland-Thomson argues, are misleading and unsatisfactory. She writes, "From folktales and classical myths to modern and postmodern 'grotesques,' the disabled body is almost always a freakish spectacle presented by the mediating narrative voice. Most disabled characters are *enveloped by the otherness* that their disability signals in the text" (p. 10, italics added). Even for those whose affective adaptions to their physical difference is not as conspicuous as (for example) the use of a wheelchair or prosthetic, many dis/abled people describe moments in which strangers have noted their difference and called attention to, or been unsettled by, its presence. As bioethics scholar James L. Benedict explains in his 2017 book on the ethics of informed consent in VCA, "The field of VCA arose in part because major tissue deficits of the face or upper extremities deprive persons of at least some of their ability to control the world, to savor the world, and to reveal themselves to others" (p. 195). As Rosemarie Garland-Thomson affirms above, a

person's authentic self remains painfully invisible to others when their identity is "enveloped" by a quality of alien appearance or experience.

In *Embodied Rhetorics: Disability in Language and Culture*, scholar of disability and social justice Rod Michalko further illustrates the difficulty of living in a society where bodily norms are presumed or required, "There is always a sense of the uncommon with me even in the most commonplace happenings. My blindness is constantly with me. It goes wherever I do. I am always 'with it' and 'in it.' My blindness is always 'with me' and 'in me.' Moreover, my blindness is always 'marked' in public. Smokie is always with me. He is in his harness and, for most, this signifies me as blind" (p. 202, "Putting Disability in Its Place" by Rod Michalko and Tanya Titchkosky in *Embodied Rhetorics* edited by James Wilson and Cynthia Liewicki-Wilson, 2001). Michalko joins scholars such as the blind writer and art historian Georgina Kleege in noting not just how *visible* their lack of vision is to others, but also the seemingly intentional ignorance practiced by many sighted writers and thinkers when portraying the experiences of the visually impaired. Kleege is both droll and lacerating in her re-presentation of the "hypothetical blind man" of philosophical thought experiments:

> The Hypothetical Blind Man has long played a useful, although thankless role, as a prop for theories of consciousness. He is the patient subject of endless thought experiments where the experience of the world through four senses can be compared to the experience of the world through five. … One of the most striking features of the [Hypothetical Blind Man] is that he is always assumed to be both totally and congenitally blind. Real blindness, today as in the past, rarely fits this profile (2005, p. 180 and 287).

According to Kleege, depictions of what it's like to be blind in the thought experiments of western philosophy are so inaccurate as to be farcical. Spectators of blindness across all types of texts—but especially academic philosophical texts—recognize and cognize blindness as a category or experience of embodied lack, Kleege argues, despite the fact that they have no notion of and indeed, no tools with which to comprehend blindness as a lived continuum of sensations, many of them experientially "positive" (see also Paterson, 2016: *Seeing with the Hands: Descartes, Blindness, and Vision*).

Due to the shallow nature of popular portrayals of dis/abled people in popular culture, disability studies scholar Lennard Davis has argued that many forms of dis/ability are deceptively "familiar" to those who do not have them. "The first assumption that has to be countered," Davis writes, "is that the 'normal' or 'able' person is already fully up to speed on the subject. My experience is that while most 'normals' think they understand the issue of disability, they in fact do not. When it comes to disability, 'normal' people are quite willing to volunteer solutions, present anecdotes, recall from a vast array of films instances they take for fact" (2017, p. xvi). Another source of wrong assumptions regarding the needs and proficiencies of people with a particular condition of difference are the supposedly sympathetic or supportive activities which celebrate difference through simulatory activities. As Alison Kafer argues in *Feminist, Queer, Crip*, asking students to, "spend a few hours using a wheelchair or wearing a blindfold so that they can 'understand' what it means to be blind or mobility-impaired" are activities which, "focus on the alleged failures and hardships of disabled bodies (an inability to see, an inability to walk) [and] also present disability as a knowable fact of the body." Kafer continues, "There is no accounting for how a disabled person's response to impairment shifts over time or by context, or how the nature of one's impairment changes, or, especially, how one's experience of disability is affected

by one's culture and environment. Wearing a blindfold to 'experience blindness' is going to do little to teach someone about ableism, for example" (2013, p. 5 Kindle edition).

According to Kafer and many other disability scholars, the phenomenal realm of dis/ability includes not just diminished access to spaces and activities that "normal" people enjoy—it also entails the endlessly disruptive and hurtful experience of being othered or to have one's condition of difference become the locus of one's identity in the eyes of others. Often enough, dis/abled persons are not just "enveloped by" disability, but reduced to it: "disabilities surface to explain everything or nothing with respect to [disabled persons'] portraits as embodied beings" (Mitchell and Snyder, 2000, p. 50). As Garland-Thomson has observed, "Cultural dichotomies do their evaluative work: this body is inferior and that one is superior; this one is beautiful or perfect and that one is grotesque or ugly. In this economy of visual difference, those bodies deemed inferior become spectacles of otherness while the unmarked are sheltered in the neutral space of normalcy" (1997, p. 7-8).

While normate people can be both effectively "invisible" and "unknown" in public, dis/abled people are both conspicuous and (as Davis argues) illusorily "familiar." Misconceptions about the needs and experiences of people with disabilities miss the reality of what makes certain conditions more or less difficult to live with on a daily basis. For instance, aspects of hand loss that are impossible to appreciate from a non-intimate perspective include the exhausting daily work of navigating a new life role or trajectory and a different orientation to others in even the closest of personal relationships. The paradoxes of applying for disability while struggling to adopt a positive dis/abled identity can be frustrating and alienating; having to ask for care and depend on others encourages humility and bond-building in addition to providing limitless daily sources for relational friction and feelings of disempowerment. As Sheila Advento describes the difficult

process of learning to rely on others for many of her daily needs, “It was so hard to accept help. I was getting really depressed, and I didn't know how to handle things emotionally. I was frustrated a lot, I took it out on people. I didn't know how to calculate the frustration into my life. I didn't know how to handle anything. I just wanted to be independent, and it was hard to ask for help, is was so hard to accept help … I did everything on my own—then all of a sudden all that's gone.”

With the above voices of dis/ability in mind, one can perhaps appreciate why people doing the work of living with disability in our society describe feeling fatigued by conversations about their differences, while at the same time having to constantly engage in political and personal arguments for their right to be included, educated, valued, and of course, allowed to live (http://disability-memorial.org/).

The “social model” of disability

The “social model of disability” is an envisioning of disability and disfigurement which is in many ways the direct opposite of that assumed by modern medical professionals. Disability scholars and activists have robustly challenged the view that, “unusual embodiment is inherently inferior” (Garland-Thomson, 2002, p. 7). Scholars and activists whose views of disability are informed by a social/relational model rather than a “medical model” argue that, “the ‘problem’ is not the person with disabilities; the problem is the way that normalcy is constructed to create the ‘problem’ of the disabled person” (Davis, 2017, p. 3). Writing on what she terms a “political/relational” model of disability, Alison Kafer locates disability not in individual deformities but “in built environments and social patterns that exclude or stigmatize particular kinds of bodies, minds, and ways of being….[as well as] in inaccessible buildings, discriminatory attitudes, and ideological systems that attribute normalcy and deviance to particular minds and bodies” (Kafer, 2013, p. 6 Kindle edition). James Wilson and Cynthia Liewicki-Wilson give a

similar perspective in *Embodied Rhetorics: Disability in Language and Culture*, insisting that, "Transforming disability … entails more than just including the disabled. True transformation would permeate the entire social order and generate changes in economic organization, ethical thought, educational practices, the organization and design of social space, and the interactions and habits of people in all aspects of daily living" (2001, p. xii).

Despite the above liberatory views of dis/ability in society, there is a somewhat contradictory thread in some of the disability studies literature that seems to demand an unmodified embrace of the "dis/abled" identity category in ways that may feel forced or inauthentic to some people. For instance, even the raucously affirming disability advocate Alison Kafer concedes that despite finding joy in communities of disabled people and valuing her own experiences as a dis/abled person, she does not want to become more disabled than she presently is (Kafer, 2013, p. 4 Kindle edition). Kafer acknowledges that a paradox exits in "…the possibility of simultaneously desiring to be cured of chronic pain and to be identified and allied with disabled people" (ibid, p. 6). We may also recall that burn survivors Joe Kinan and Carrie Pratt—also strong advocates and activists on the part of people with disabilities or physical differences—signed up for a risky and potentially burdensome experimental treatment for a chance to gain more independence and functionality in their lives (see chapter 2). Social models of disability that invite positive participation in dis/ability as an identity category also suffer in the sense that disabilities can be more dynamic than other cultural markers—conditions of disability or chronic illness wax and wane throughout the life course, taking on different meanings and statuses. As Rosemarie Garland-Thomson writes in *Extraordinary Bodies*, "The physical impairments that render someone 'disabled' are almost never absolute or static… Some conditions, like multiple sclerosis or arthritis, are progressive and chronic; others, such as epilepsy, can be acute. Even seemingly

static disabilities like amputation affect activities differently, depending on the condition of the rest of the body" (1997, p. 13, italics added).

In their 1988 book on the lifetime management of chronic illness, *Unending Work and Care*, sociologists of science Juliet Corbin and Anselm Strauss summarize these learned social reactions to and associations about disabilities that, "Having a chronic illness or disability may well be acquainted with having a failed body. Illness aside, whatever one chooses to do, physically or mentally, usually assumes that one has a functioning body capable of carrying out the desired activity" (p. 7). Indeed, the first doctor I interviewed for my master's project on hand transplant history called the phenomenon of losing a limb "upper extremity castration" to indicate his understanding of a unique category of relational impotence stemming from hand loss. In my oral history narratives (see chapter 3) the physical difference of upper extremity loss is experienced by many narrators as embodied inferiority. Several hand transplant recipients or one-time candidates for hand transplantation have made comments such as, "I'm 'on disability' but I'm not 'disabled'." Most of my narrators with unique arms or hands saw themselves as, and *wanted to be seen as*, autonomous, strong, capable, unique, even *fun*, people—and most naturally wished to signal their self-sufficiency and sense of social value to others. Unfortunately many experienced difficulty signaling their own normalcy, self-sufficiency, and vitality to others when they lost their hands because for strangers, this lack signals a person as impotent or (apparently to some) incompetent.

Angel Gonzales relates the frustrating arc of his and his partner's relationship with the outside world following the latter's quadrilateral amputations:

> I think people respond to the [transplanted] arms in a way that is … different … from the way that they respond to someone who has all four limbs gone, you know what I mean? Like they can almost accept that he's in a wheelchair because he has

> no legs, but you know they kind of freak out when he has no legs and no arms they're like "whaaoouo" you know? But now that he has arms it's a little bit easier to be out in public , not that we cared either way it's just—for the sake of other people, it's easier to be outside, with the arms. Um, you know what I mean, like, they seem to respond less to him um, in this pitying way or in this kind of freaked out way where they would come and address *me* about his condition. You know [in those cases] it's like, "He's right in front of me," or you know what I mean um, that would happen if we would go shopping at Trader Joe's and I would be like, uhhh, "He's right there!" (laughter) ..."I would just kind of shrug and give them a quick answer and keep moving, um, which is actually something a [physical therapist] taught us.

For Rich and Cindy Edwards, the responses of strangers to the sight of Rich's injuries and the loss of face, so to speak, that he felt in public based on other people's staring was one of the hardest aspects of trying to navigate life following burn trauma. Cindy narrates, "Rich couldn't live like this like the way it was. People were always staring at his hands. Children were always staring and pointing. Even though he can't do hardly anything with his hands right now, at least they look mostly normal." As I was completing the descriptive codes for my oral history interviews, the code "Other People"—referring to instances in which narrators recalled

Rosemarie Garland-Thomson has pointed out that acts of staring can be an inward journey as well as an outward gesture, when starers are made self-aware and an engaged rather than individual experience unfolds via this recognition:

> Triggered by the sight of someone who seems unlike us, staring can begin an exploratory expedition into ourselves and outward into new worlds. Because we

> come to expect one another to have certain kinds of bodies and behaviors, stares flare up when we glimpse people who look or act in ways that contradict our expectations. Seeing startlingly stareable people challenges our assumptions by interrupting complacent visual business-as-usual. Staring offers an occasion to rethink the status quo (2009, p. 6).

Responses of society to disability and embodied difference are also plastic and dependent on circumstances, having historically been determined by prevailing social attitudes on the moral status of a marking differences (including questions of heritability and the circumstances leading to acquired conditions) in making decisions on how to care for or otherwise manage the presence of non-normate individuals. As a group of medical ethicists and psychiatrists write concerning the public "acceptability" of novel forms of reconstructive transplantation following hand transplants, Sarwer et al write that, "Perception of personal sacrifice and accountability for facial trauma plays a role in public endorsement of face transplant. Transplant to ameliorate injury sustained secondary to military service garners nearly universal support. Victims of disfiguring accidents receive substantial support as well, though transplantation is valued more highly for 'blameless' accidents than for accidents partly resulting from the victim's own actions" (p. 28-29).

In a related example, a surprisingly charitable attitude towards individuals with inadvertently acquired physical disabilities in Nazi Germany inspired a proliferation of assistive technologies for that population even as the same administration sought to end the existence of people whose difference was considered both unwanted and "innate." Historian Robert Jay Lifton writes, explaining how superficially progressive resources for the treatment of people with certain disabilities aided Nazi narratives that their doctors were ethically and scientifically administering medicine:

> [A]t the same time that they developed a policy of sterilizing or killing people considered unfit for a society of the strong, the Nazis boasted of spectacular results and humane employment arrangements for people who had lost hands or limbs, especially in combat. In these ways, most doctors could continue to view themselves as authentic physicians, whatever the degree of Nazification of their profession (1986, p. 40).

In western cultures where restoring the so-called "usefulness" to society of disabled persons is considered a good, strategies for mitigating disability directly by healing/restoring the bodies of affected persons are praised for their power to remove a source of unwanted difference—even as more discernibly eugenics-informed erasure of disabled *persons* has lost public and professional approval. Today the trope of astonishing restoration of disfigured bodies to healthy norms can be encountered in nonfictional settings as diverse as TV journalism, scientific papers, direct-to-consumer prescription advertising, and the rhetoric of holistic and religious healers. As Kafer has restated from a selection of science news articles: "Thanks to new developments in medical technology, we are 'soon' going to be living in an era when 'brainpower will let the paralyzed walk, [and] allow the mute to speak.'" She adds matter-of-factly that, "Enabling 'the paralyzed' to walk is one of the most common expectations for [medical] technologies" (2013, p. 107 Kindle edition).

4.3 HOW DID WE GET HERE? MEDICALIZATION, BIOMEDICALIZATION, AND HAND TRANSPLANTATION

As western medicine advanced in the 20th century, the processes referred to by science scholars as "medicalization" entailed the scientific measuring, sorting, mending, disciplining, and instructing of patients and communities under the authority of emerging scientific standards and field-specific best practices. As STS scholars Clarke, Mamo, Fosket, Fishman, and Shim describe these transformations:

> Historically, the rise in the United States of Western (allopathic) medicine as we know it was accomplished clinically, scientifically, technologically, and institutionally from 1890 to 1945. This first 'transformation of American medicine' was centered not only on the professionalization and specialization of medicine and nursing but also on the creation of allied health professions, new medico-scientific, technological, and pharmaceutical interventions, and the elaboration of new social forms (e.g., hospitals, clinics and private medical practices) (2009, p. 50).

The "medicalization of society" has been theorized and documented by sociologist Peter Conrad, who explains, "The main point in considering medicalization is that an entity that is regarded as an illness or disease is not ipso facto a medical problem; rather, it needs to become defined as one" (2000, p. 182-184 Kindle edition). Disability scholar and literary theorist Arthur W. Frank has called this phenomenon, "the modernist expectation that for every suffering there is a remedy" (2013, p.80 Kindle edition). Early hand transplant ethicist Mark Siegler, arguing on behalf of a clinical attempt at hand transplantation, exemplifies this point of view when he writes in 1998 that, "The public expects that previously untreatable medical and surgical conditions will

yield in time to scientific research and that novel treatment developed by clinical scientists will be introduced into practice with a minimum delay" (1998, p. 2782).

"The consequences of this master narrative," Frank goes on to say, "are complex." Of course, physical and cognitive disabilities of all kinds have become the objects of much medicalized attention, little of which has been objectively or even superficially oriented toward the benefit or well-being of the communities targeted for interventions. Media and disability studies scholar Fiona Kumari Campbell has lamented that among the insults and injuries of medical science toward people with disabilities is the apparent lack of interest shown in generating healthcare products and services that respond authentically to dis/abled individuals' *actual* needs. Campbell argues that, "Medical practices, organized around the medical model, presume that the doctor's task is to diagnose diseases, to discover their causes and symptoms, and design treatments. Any knowledge standpoint of the patient [on this model] is sloughed off" (2003, p. 443). In a similar vein of critique, Alison Kafer scornfully reviews medically driven efforts to normalize physical and cognitive difference in her 2013 polemic, *Feminist, Queer, Crip*, writing that the medical model of disability, "frames atypical bodies and minds as deviant, pathological, and defective, best understood and addressed in medical terms. In this framework, the proper approach to disability is to 'treat' the condition and the person with the condition" (p. 5, Kindle edition). Kafer reminds readers that normalizing "treatments" for disability and physical disfigurement have been justified "on the grounds that such acts will lead to better futures for the disabled person and/or for their communities" and she reminds readers that such efforts have included: "everything from sterilization to institutionalization, from bone-lengthening surgeries to growth attenuation" (ibid, p. 29-30).

The healthcare processes of "biomedicalization" have arisen alongside those of medicalization in recent decades as a more networked, information-driven orientation to biomedical research and delivery, facilitated by 21st century advancements in data science and biotechnology. As STS scholars Adele Clarke, Janet Shim, Laura Mamo, Jennifer Fosket and Jennifer Fishman write in their 2003 article theorizing biomedicalization, "Biomedicalization describes the increasingly complex, multisited, multidirectional processes of medicalization, both extended and reconstituted through the new social forms of highly technoscientific biomedicine" (p. 162). Unlike traditional western medical approaches which produced their effects through the discovery and disciplining of molecular and behavioral activity, according to Clarke and colleagues, "The historical shift from medicalization to biomedicalization is one from control over biomedical phenomena to transformations of them. … [Biomedical] innovations and interventions are not administered only by medical professionals but are also 'technologies of the self,' forms of self-governance that people apply to themselves (p. 167).

I believe it is via the criteria of 'biomedicalization" not "medicalization" that hand transplantation is mostly accurately characterized and critically viewed. Whereas traditional "medicalized" treatments for upper extremity loss or injury have aimed to return discreet aesthetic or psychosocial function(s) at the site of injury, the radical transformation of a patient's care trajectory necessitated by hand transplantation—where a candidate essentially moves from "healthy" amputee to post-transplant "patient" indefinitely—requires individual and community "buy-in" on a level that is unprecedented by even the most invasive brain-controlled prosthetics.

Because prosthetics necessarily come on and off (an annoyance remarked on by almost all narrators for this project) their use or disuse does not command a change ontologically or even nominally to the user's Self or how they think of themselves. By contrast, hand transplantation

involves protracted somatic and behavioral changes which are experienced by recipients and their families as genuine transfigurations of their identity and/or lifestyle. During a 2008 panel on transplantation innovation at the Clevelend Clinic, Dr. Thomas Starzl (considered by many to be the "father" of modern organ transplantation), described related phenomena succinctly when he said, "Putting a new hand or face on someone is astounding. It changes the morphology of the brain, which can be observed with functional magnetic resonance imaging. It changes the soul, if that is what you want to think of when talking about the brain" (Cooley et al, 2008, accessed online). This approach of wholesale transformation rather than localized restoration is consistent with the processes of biomedicalization as through hand transplantation, recipients' lives are profoundly enmeshed with the evolving biotechnologies and "self" technologies of immunological monitoring, graft rehabilitation, and maintenance for as long as they have their hand graft. Such robust alterations of routine and self-understanding have been recognized as challenges in selecting "ideal" patient candidates (Taylor-Alexander, 2014) for hand transplantation as prospective patients are judged based on their ability to withstand and participate fully in the transformation, hybridization, and collaboration needed to make a hand transplant work.

Viewing HTX procedures and outcomes through the concept of biomedicalization gives us tools for understanding which support activities and rhetorical strategies might produce or undermine a person's quality of life through hand transplantation. In a biomedicalized society, novel constructions of wellbeing coalesce around emerging and pre-existing concepts of illness and the "multiple" or entangled body (Mol, 2003; Shildrick et al, 2017) as, for instance, online communities of people identifying "with" or "as" a particular medical condition form to equip themselves with rapid-cycling knowledge about their condition, and to develop tools for collective bargaining on available treatments. Adversely, biomedicalized approaches can entail a greater

requirement for surveillance or more invasive access to personal data by medical experts, and can create uncertainty/precarity which is experienced as a risk state by participants.

As can be witnessed in the oral history chapter of my dissertation (chapter 2), the new layer of stress, labor, and "precarity" added to the lives of hand transplant caregivers by these procedures is a repeating feature, even when narrators ultimately expressed satisfaction with the hand transplant. "Uncertainty, referring here to doubt about how to act, is a well-known challenge in healthcare. … Medical uncertainty has a deep moral and existential dimension: *it provokes fundamental questions about whether lives are worth living*, about balancing potential with risk, and about weighing danger against benefit," Write Stefan Timmermans and Mara Buchbinder citing Renee Fox's ideas on this topic. The authors continue, "Fox emphasized that uncertainty could not be dispelled with scientific or technological advances. She drew attention to the recursive nature of uncertainty: while technologies may address some forms of uncertainty, they seem bound, inevitably, to uncover previously unrecognized forms of uncertainty or to produce new ones" (2012, p. 13, italics added). Because "uncertainty is inevitable whenever new technologies produce previously unavailable knowledge about patients" (p. 14), the passage by Timmermans and Buchbinder could be easily be applied to describe the situation encountered by hand transplant patients: these surgeries may create more uncertainty than they dispel about whether life will be "worth living" after the intervention. The threat of rejection—which must be constantly monitored and protected against—and the specter of life-threatening complications from immunosuppressant drugs attend all gains to lifestyle and self-description following hand transplantation. (Despite these factors, efforts at dispelling uncertainty in the VCA field so far have not included efforts to ask patients why and how the surgery worked to transform their lives; as above the "gaze" of most papers in the literature has been on measuring duration and function of grafts, identifying

molecular processes of immunomodulation, and classifying variables of acute and chronic rejection.)

Conclusion

This chapter offered a rhetorical reading of representations of hand transplant outcomes in medical literature, demonstrating the emphasis on preselected criteria for effectiveness and declarations on how protocols for managing rejections and infections were sufficient to allow the hand graft to continue. This narrow view of success is in sharp contrast with the patients' accounts offered in the previous chapter, as well as insights from STS and disability studies. The chapter ends by calling for more authentic methods of representing patients' experiences and for connecting the "success" of medical experimentation to actual factors impinging on patients' quality of life.

Recognizing the range of meanings and values *attributed to* a hand transplant, and the new sources of meaning and value *afforded by* a hand transplant in the lives of recipients and their families, enables diverse stakeholders to understand how very personal, subjective factors must be accommodated in quality of life assessments both prospectively and post-transplant. Physicians and ethicists working to improve the process of hand transplantation operate blindly when they cannot accurately envision the factors contributing to past successes and failures; qualitative and quantitative approaches are needed to understand outcomes in this and other fields of transplantation (Shildrick et al, 2017). Of course, if narrative or other phenomenologically oriented methods are to be deployed more systematically across the hand transplant field, patients should have a say in determining how their feelings and experiences are emphasized in medical representations and how their personal reflections are "sliced and diced" so to speak, as data. Thus, in closing and in the next and final chapter of my dissertation, I argue that more research on the

ethics of representing others in academic medical journals (either as persons or as abstractions) is needed.

5.0 CONCLUSION

"Never turn your attention off, and always show respect for what people choose to tell you. This was the first reason I listened; the second reason was that the stories were beautiful and well-told, and I knew that there's no beauty without meaning (aesthetics is not merely ornament and appreciation; it is a form of knowledge)."

~ Alessandro Portelli, *The Death of Luigi Trastulli*

Ten years since I began studying the history, outcomes, and ethics of human hand transplantation (HTX), my understanding of the value of these surgeries has been informed by conversations with amputees, hand transplant recipients and their caregivers, doctors and researchers in hand transplantation/reconstructive transplantation, and crucially, by my readings in academic disability studies. My final conclusion based on the arguments and observations presented above is that hand transplants are ethically complicated, lifelong interventions that require, above all else, a team of care providers who are committed as their first priority to the health and well-being of their patient recipients, not to advancing the science of the field or their own professional interests.

In this dissertation, I have shown that where outcomes of experimental operations are reported in the detached parlance of objective science, discerning the lived experiences of patient participants can be nearly impossible. I discussed how hand transplants received major coverage in news media even though they represent minimal achievement surgically and scientifically—the main development making HTX possible at the turn of the 21st century was interdisciplinary coordination and reexamination of transplant ethics and this work was accomplished *discursively.*

This is important, I argued, because almost all of the rhetorical heavy lifting giving rise to HTX relied on the promise of "beneficence," or the idea that HTX present an opportunity to improve the quality of life (QoL) of a vulnerable population of care seekers despite the known burdens of immunosuppression and steroids.

The very notion that "quality of life" could be a site of intervention for organ transplantation has been called "a quiet revolution in organ transplant ethics" by prominent bioethics scholars. Nevertheless, twenty years after the first speculative discussions on the risks and benefits of hand transplantation, the specific nature of these tradeoffs in human experience are still unclear. As I revealed through my interpretation of HTX oral histories in chapter 2, the nature of quality of life effects after hand transplantation are far more challenging, person-specific, complicated, and drawn-out than medical case studies and reviews represent. Because for bioethicists and surgeons it has always been a narrow question of balance whether hand transplants are permissible, the specific nature of quality of life tradeoffs for HTX patients should not be going unexplored in this field, since patient-centered policies and procedures in hand transplantation cannot be developed without access to qualitative data which take into account the large-scale impact of these surgeries on patients' lives.

Finally, in chapter 3 in undertook a close rhetorical reading of representations of HTX outcomes in medical discourse showing how clinical stakeholders depict hand transplant outcomes as "successful" through a series of gestures that include recitations of preselected criteria for effectiveness and declarations on how protocols were deployed to efficiently manage complications like rejections and infections. However—as I show through my discussion of theory in disability studies and STS following the rhetorical analysis in section 1, the lived reality for patients "beyond the lines" of these texts could be very different from the sanitized progress-

oriented depictions of HTX professionals. More work must be done, I argued, to determine more authentic, accurate methods for representing subjects of medical experimentation, especially in treatments that seek to improve patients' quality of life.

The ethical dimensions of my dissertation are significant and urgent. The hand transplant field has evolved and expanded rapidly without robust knowledge of what has happened to, or is going on with, existing patients. The exceptionally limited number of recipients (N= <100) means the hand transplant field suffers from shortage of data as a fundamental problem. Indeed, the value of direct, peer-to-peer consultation with knowledgeable "people like me" is a recurring theme across my oral history interviews, yet because competitive research programs are geographically and intellectually siloed, a central meeting place for information exchange (intellectual perspective) and affective connection has not been organically facilitated. Efforts to rehabilitate hand transplantation will, in my opinion, begin with serious international conversations on the ethics of representing patients and other vulnerable stakeholders (either as persons or as abstractions) in this field, guided by a patient advocacy and support network.

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